

COMPLETE TRANSCRIPT

Senate Select Committee on Autism and Related Disorders

Darrell Steinberg, Chair

Health Insurance Coverage of Behavioral Intervention Therapy for Autism Spectrum Disorders (ASD)

**Thursday, June 10, 2010
State Capitol**

SENATOR DARRELL STEINBERG: Good morning, everyone. The Senate Select Committee on Autism will come to order. This is a select committee which means it's not a committee that will cast votes on any particular measure or bill. I want to welcome all of you today, and I knew that there would be a crowded hearing room and I was right because of the interest in the issues we'll be discussing today.

I also want to welcome my colleagues in the state Senate—the Republican leader, Dennis Hollingsworth; the chair of the Senate Health Committee, Elaine Alquist; and the incoming leader for the Senate Republican—Senator Bob Dutton. Welcome to all of you today.

I'll make some brief opening comments and then allow my fellow senators to do the same, if they choose, and then we'll get right into the hearing itself.

We convened the Senate Select Committee on Autism and Related Disorders because we recognize here in the Senate, and obviously in a bipartisan fashion, that autism and autism spectrum disorders are affecting tens of thousands of California families, and most of the work of this taskforce has been done under the auspices and leadership of Dr. Lou Vismara and, even more importantly, by many of you in the audience, as these regional and

subject matter taskforces have worked over the last year to bring back a series of recommendations to this select committee that we then begin to take and analyze.

We all know the statistics about autism—how it's the fastest growing disorder, about the number of children and families affected, and I won't go over that again. We also know that there is great hope out there, both on the research side and on the treatment side, and that every year that passes with quality research and quality professionals and quality providers, that kids living with autism or autism spectrum disorder are getting better and better and that more kids have a chance for a productive and a healthy life.

The last hearing was wide ranging in terms of a report back from the various taskforces on the work that is being done—about early intervention, about transition for 18 year olds who move from the system, so to speak, to adulthood—I want to welcome Senator Curren Price as well, and thank you for coming.

Today we want to focus on what might be a more controversial piece of the debate here, and that is, the role of health plans and the role of our public school system in paying for ABA therapy. ABA therapy is not necessarily new but increasingly recognized best practice in terms of helping kids with autism and autism spectrum disorder. And the issue before us today is who pays for this therapy and whether the therapy itself falls more on the medical side, if you will, of the spectrum or on the educational side of the spectrum. And we're going to hear a wide range of opinions here, not just to have it out publicly here. We don't want to point—we don't want this to be a finger-pointing hearing. We want this to be a hearing whereby the end we can all see a pathway towards the only thing that matters, and that is, making sure that more families and more kids have access to this therapy, period, and I think we can get there. I know we can get there.

We have a number of panels—the Science and Treatment, first of all, of autism spectrum disorder, the Regulatory Framework for Private Insurance Coverage of ASD Services, the Health Plans' Perspective, and, of course, last

but certainly not least, the Challenges Faced by Families as they try to navigate the system. We'll also have a little time for public comment and we will wrap up.

A number of us are involved in the budget and in other matters, and so you may see us going in and out of the hearing, including myself, throughout the day. Don't take that as anything other than the fact that we're trying to juggle a number of responsibilities.

All right. My colleagues, anything you want to add to the record?

Senator Dutton?

SENATOR ROBERT DUTTON: Yes, just briefly, and I'm glad you mentioned that because I actually will be heading off to Conference Committee right now on the budget, but I wanted to introduce Michelle Clark. She's from my office. She's going to be here. It certainly is an area that I have a lot of great deal of interest in, and so I just wanted to let everybody know that my absence is not due to lack of interest and I do have Michelle here that's going to be getting the information for me so that I can be better informed as to what we're doing, so thank you Mr. Chairman.

SENATOR STEINBERG: Thank you.

Senators Price, Alquist.

SENATOR CURREN D. PRICE, JR.: Thank you, Mr. Chairman. I just wanted to thank you for your leadership on this issue. Certainly these issues sometimes disproportionately impact communities of color, communities where there are historic healthcare disparities, and so we're anxious to keep the discussion moving forward and to be cognizant of the impact on all of our communities as it relates to this. I was pleased to convene the taskforce, Autism Taskforce, in my district. We've had some very good discussions with a number of stakeholders on some of these issues, and so I look forward to the discussion today and making the contribution.

SENATOR STEINBERG: Very good. Thank you, Senator Price.

Senator Alquist?

SENATOR ELAINE KONTOMINAS ALQUIST: Well, first of all, I'd like to thank you, pro Tem, Darrell Steinberg, for your leadership for heading this—and also Dr. Vismara. I really believe that one of the main reasons we are all sitting here is because of your great heart.

SENATOR STEINBERG: His great heart.

SENATOR ALQUIST: Both of you. (Laughter) You both have great hearts—or in Greek—kalés karthies.

As a member of the Senate Select Committee on Autism, I've been pleased to work with the Bay Area Autism Regional Taskforce which I know has been stellar—right, Santi? (Mr. Santi Rogers, Executive Director, San Andreas Regional Center)—has been stellar in this area. And I also know that Feda Almaliti has been a tremendous advocate.

I won't go over many of the things that Senator Steinberg has mentioned. We all know about the autism tsunami; just like we're facing a silver tsunami, we're facing exponentially an autism tsunami. But some things that I do need to mentioned, one is, that I am troubled to hear that parents are in encountering insurance barriers when trying to get the necessary treatments for their autistic children.

I have grown sons. I am a Yiayia—that's a Greek grandmother—and I can only imagine—and a former schoolteacher and school counselor, and I can only imagine how frustrating it is for you to know what needs to be done. I am sure that so many of you have done great research. And when we talk about the particular therapy involved and how it should be covered, you know, this is the year 2010 and we ought not to be just doing things the way we did in the 1980s. So I have all kinds of reports that Lisa, my consultant, brought forward that I'm not going to mention, but it's the Surgeon General's Report on Mental Health 2001, the 2007 Clinical Report by the American Academy of Pediatrics on the benefit of ABA therapies, and many, many more. But the main thing is that we want to hear from you and we need to be educated and to learn how you want us to proceed. Again, I'm very pleased to be a part of this.

SENATOR STEINBERG: Thank you very much, Senator.

Okay. Let us start out. I want to make one more welcome, and that is, just to welcome Dr. Barbara Firestone who was the co-chair of the Blue Ribbon Commission on Autism which preceded the Senate Select Committee and she is great. That's all I'll say. Okay?

Let us begin with the Science and Treatment of Autism Spectrum Disorder, and let me welcome my friend David Amaral, director of Research for the UCD MIND Institute and a distinguished professor, Department of Psychiatry and Behavioral Science and Center for Neuroscience, School of Medicine, at UC Davis—that is one long title, let me tell you something—Sally Rogers, Ph.D., Dr. Sally Rogers, professor, Department of Psychiatry and Behavioral Science, also at UC Davis; and Robin, Dr. Robin Hansen, M.D., the director of Clinical Programs of the MIND Institute and many other things, okay?

Let us go in order here. We'll begin with Dr. Amaral. This panel is scheduled for about 20 minutes, so I'm going to ask you to keep your comments in line with that timeframe, all right?

Thank you, Doctor.

DR. DAVID AMARAL: Good morning...

SENATOR STEINBERG: Good morning.

DR. AMARAL: ...Senator Steinberg and other members of the Senate, the Senate Select Committee on Autism and Related Disorders, distinguished colleagues, and ladies and gentlemen, autism spectrum disorders are a group of behaviorally defined, severe disorders of brain development affecting one in 110 children and more likely to occur in males than in females. The causes of autism remain unknown.

Some of the first signs are unusual emotional behavior, reduced social interest, and poor eye contact that begin to be seen about one year of age. By three years of age, a child may be given a diagnosis of autism if they display three core behavioral features: impairments in reciprocal social interactions, abnormal development in use of language, and repetitive and ritualized behaviors, and a narrow range of interests. In addition to these core features

of autism, there are common co-morbid, neurological disorders, such as epilepsy, anxiety, and sleep disorders. And many individuals with autism have severe to moderate delays of cognitive development. Beyond the nervous system, many individuals with autism have troubling gastrointestinal problems and some have dysfunction of their immune system.

I've been asked to address the question, Is autism a brain-based medical disorder? Medical disorder is an abnormal condition of an organism that impairs bodily functions associated with specific symptoms and signs. As I've already described, individuals with autism have impairments in their ability to communicate, to interact socially, and to refrain from habitual, repetitive behaviors. The brain is the organ that coordinates all of these activities, and more than a century of neurological research has shown that damaging certain systems within the brain—through stroke or other disease states, can lead to deficits in these functions. So while the infamous early days of autism study led to the conclusion that the disorder was purely a “psychological” problem due to faulty parenting, this view has been entirely repudiated. There is now absolute consensus in modern medicine that autism spectrum disorders are the result of abnormal brain functioning, the causes of which are many and complex.

What do we know about the genetics of autism? We've actually learned more in the last five years about the genetics of autism than in the previous 30. What this new information has taught us is that autism is extraordinarily complex. In fact, many scientists think of autism as a group of biologically distinct syndromes that all result in the same behavioral problems. We now know that genetic abnormalities account for at least 20 percent of autism cases. However, interestingly, none of the known genetic causes accounts for more than 1 to 2 percent of cases of autism. There is accumulating evidence, however, that despite the heterogeneity in the genes that may put an individual at risk for autism, many of the consequences lead to a dysfunction of the synapse, the all-important microscopic region of the brain where one neuron communicates with another.

What do we know about the neurology of autism? When you take a magnetic resonance image of the brain of a child with autism, as we do every day at the MIND institute, there's no obvious or dramatic difference in its size and shape. In fact, for years scientists have been frustrated by the apparent subtlety of the pathology of the autistic brain. But in the last five years, a series of studies of very young children with autism have shown that certain select parts of the brain actually mature too fast. This is only apparent if you take an MRI annually and chart the growth curve of brain development. So you might ask, Why is it bad that some parts of the brain are maturing too fast? We believe that the maturation of the 100 billion neurons in each brain is a highly coordinated process that requires all brain regions to keep to a prescribed timing, just like musicians in an orchestra. If one part of the brain matures too rapidly and tries to establish connections with other parts of the brain that are not ready for them, then they are rejected and abnormal connections form.

The part of the brain that has been most consistently demonstrated to mature too rapidly is the frontal lobe, just behind the forehead. This part of the brain mediates facets of social behavior, as well as language function, and planning motor actions. Work being conducted at the MIND institute has demonstrated unequivocally that in the autistic children with rapidly growing frontal lobes, the connections from the frontal lobe are very highly abnormal.

So let me summarize thus far. There is increasing evidence for genetic deficits that increase the risk of having autism. Most of the implicated genes are known to affect either brain development or synaptic communication. When you look at the brains of children with autism, the most consistent finding thus far is an abnormal growth trajectory that leads to abnormal patterns of connections in the brain, particularly in the frontal lobe. All of these data support the conclusion that autism is a brain-based medical disorder.

I'd like to make two final points.

First, the brain of a newborn child is only about 30 percent of the size of an adult brain. By five years of age, the brain has reached 95 percent of its adult size. Therefore, during the period when autism is diagnosed, the brain is going through a rapid maturational process where new pathways and new connections are established. Something in this process seems to be going awry in children with autism.

My second point is that maturation of the brain connections is heavily reliant on interactions with the environment. It's just not a free-running program. Let me give you an example, and the research that I will briefly summarize led to the Nobel Prize for neuroscientists David Hubel and Torsten Wiesel in 1981. The left side of the visual cortex receives input from both eyes, both the left and right eye. And the connections from each eye occupies different territories, different territories in the visual part of the cortex. If one were to do an experiment with a very young cat in which you put a patch over one eye, which blocks visual information from the environment getting to the brain and keep it there through a critical period, once you remove the patch, that eye no longer works. The animal is blind on that side. What is most interesting is that the brain territory that would have been occupied by connections from the patched eye has been taken over by the functioning eye. There is a saying in neuroscience that neurons that fire together wire together. Since the neurons associated with the patched eye were not firing, because they weren't getting any environmental stimulation, they did not form functional circuits in the brain.

So let me be clear, while the structure of the brain and how its circuits are wired together is critical to the production of normal behavior, it is equally true that the behavior and experience of the individual are critically important in the normal construction of the brain. It's a two-way road.

In autism, we believe that some of the genetic and brain problems that I have described makes the child less inclined to engage in social activities and communication. Normal social interaction, like normal visual input, is essential in order for the social brain to be connected properly. Without

intervention, the mis-wiring of the social brain proceeds and the child may have a permanent disability. But in the cat experiment that I mentioned of Hubel and Wiesel, they found, if they took the patch off the one eye and placed it on the other eye for a period of time, they could force the connections to become restored and the cat would be able to see normally.

It is our strong conviction that intensive behavioral therapy can materially affect the development of brain connections and decrease or remove the lifelong disability of autism. With that, my colleague, Dr. Sally Rogers, will now elaborate on that theme.

DR. SALLY ROGERS: Thank you, Dr. Amaral, and thank you, Senator Steinberg, Members of the Senate Select Committee on Autism and Related Disorders, and colleagues and audience for the opportunity to talk with you today. I wanted to talk with you about the role of behavior therapy and the interactions of behavior therapy in educational interventions for children with autism.

The symptoms of autism, like those of many other physical and mental health conditions, respond very well to interventions that are designed to replace maladaptive behavior and patterns of behavior with more appropriate behavior. Treatment approaches that focus on changing behavior are used in many different medical conditions—not just autism—including addictions, depression, obsessive compulsive disorder, eating disorders, aphasia, brain injury, just to name a few. These treatments are administered by a wide range of health-related professionals, including psychologists, psychiatrists, speech and language therapists, nutritionists, psychiatric social workers, occupational therapists, behavior analysts, and many others.

Effective approaches that are used to change people's behavior build more appropriate skill repertoires for people, and they reduce their use of inappropriate behavior, and these approaches come from years and years of research on learning principles and behavior-change principles that underlie behavior therapy. The basic approach follows the principles that behaviors that help a person achieve their goals become stronger in their behavioral

repertoire, and those behaviors that do not help people achieve their goals become weaker over time. These same principles can help nonverbal people learn to speak, can help people stop hurting themselves and hurting other people, and can help people learn to respond appropriately when others speak to them and try to help them. This is true for people with autism and people with many other kinds of neurological problems.

The effectiveness of behavior therapy for medical conditions, including autism, has been examined in hundreds to thousands of scientific studies, and this is considered the most effective medical treatment for autism and for many other medical disorders. Behavior therapy is a medically necessary treatment for autism, and recent research at the MIND Institute, beginning as early as 12 to 18 months, demonstrates changes in children's lives, as David was describing, based on young brains and immature levels of functioning, which are shaped through behavior principles into more typical ways of functioning and have changes that appear to last a lifetime, according to studies that we have in the field.

Each one of the core symptoms of autism, those caused by the biology of autism, is effectively treated using behavior therapy. The core symptoms involve three groups of behavior:

- Abnormal patterns of language development and language use;
- Abnormal social behavior, which includes lack of interest in others, lack of empathy, failure to share experiences and interests with other peoples, and lack of social engagement of peers and family members, and;
- Abnormal repetitive motor movements—repetitive talk, repetitive actions and rituals, repetitive thoughts, and obsessions.

These biological symptoms of autism are all present in all people with autism, from infancy to old age, and from people with the mildest to the most severe symptoms. And all of these treatments respond positively to behavioral

interventions designed to stimulate use of more typical behavior. As in other medically necessary treatments, use of behavior therapy requires individualization to each individual person based on each person's unique characteristics, and it must be designed by a professional with training and expertise in the use of behavior therapy. However, as in many other kinds of medical therapies, the interventions themselves, once designed and supervised, can be delivered by many other people, including therapy assistance and others being supervised by professionals in charge, which we also see in physical therapy and occupational therapy, and this allows for much more economical approach to providing treatment.

People with autism of all ages and all severity levels can respond well to carefully designed behavior therapy interventions. However, scientific evidence suggests that the very young child with autism is particularly responsive to these interventions and can greatly improve in all areas when these therapies are carefully designed and delivered intensively in the first few years of life due to the plasticity of an infant's brain, as David just described, and the speed with which young children learn. We see this same effect of early childhood in other disorders, like deafness and brain injury, and we are currently studying this at the MIND Institute with interventions aimed at infants as young as six months of age, who show high risk of autism. We are confident that earlier and earlier well-focused interventions may result in very, very drastically enhanced outcomes for people with autism, and that's the challenge of our futures, to deliver that as early as possible, to get those kinds of improved outcomes, and reduce long-term costs for health insurance and for society in general due to the disabling condition of autism.

However, in addition to having the core, biological symptoms of autism, many people with autism also have cognitive impairments that result in slower learning rates in general. For infants and toddlers, this is part of the biology of autism. But for preschool and school-aged children and youth, these cognitive impairments affect their ability to learn in school. For school-aged children, we're talking now about educational handicaps, and these are addressed in

schools through the Individual Educational Plan, the IEP, which lays out strategies for helping children achieve the State Educational Standards for their grade levels. Educational funds support schools to carry out the IEP and support children's academic learning.

Thus, children and youth with ASD generally have two sets of intervention needs—those that address their biologically based core symptoms of autism and those that address their educational needs. How do we determine which set of symptoms a treatment is addressing? How do we determine when health coverage should be funding treatment and when educational funds should be used? Looking at the credentials, the professional will not suffice since many different professionals use behavior therapy techniques in both settings to achieve both sets of goals. However, well-written treatment plans always specify what the target symptom is that is being treated by the plan. One way to make the decision—and it's just one way—but one way to make this decision about division of treatments between educational and medical treatments is to examine the target symptom. If the target symptom involves one of the State Educational Standards, then the intervention can be seen as educational and it should be addressed by the IEP. But if the target symptom...

SENATOR STEINBERG: Can you give you an example? I mean, you're getting right to the core here.

DR. ROGERS: Yes.

SENATOR STEINBERG: So can you give an example of a targeted symptom that would be educational in nature versus medical in nature?

DR. ROGERS: Certainly. So an educational standard for a five year old in kindergarten right now in the state of California involves a kindergartner who will know the covers of a book, will recognize the letters of their name, will be able to count number of objects. Those are educational standards that are expected by all kindergartners, that if a child with an IEP, a kindergartner with autism, those skills leading to those abilities should be part of their IEP because that is the educational standard.

On the other hand, not responding with eye contact when a peer member initiates play or not being willing, not being able to speak to communicate your needs, those are not educational standards. That's basic equipment that all kindergartners have at the start of kindergarten. Those are the specific targeted medical symptoms of autism and they appear in every diagnostic medical system involved in autism. Those are target symptoms for the core medical aspects of autism.

SENATOR STEINBERG: Thank you.

DR. ROGERS: Does that clarify what I meant?

SENATOR STEINBERG: Yes.

DR. ROGERS: Okay. Thank you.

So the target symptoms can be looked at in this way. Is it addressing the medical distinctions that are listed in medical technology and medical diagnostic systems, or is it part of the standard curriculum described by our state? And this isn't a method that we can use to decide when medical sources should be funding behavior therapy, regardless of who's delivering it and when educational funds should be used.

So to conclude, behavior therapy applies the science of learning to change behavior. It's the most effective treatment for many medical disorders, including ASD, and it is the most successful treatment that we have for the core symptoms of ASD, for people of all ages and all levels of severity. It is medically necessary treatment for ASD. And while it can be used—it can be used to deliver both educational goals and targeted medical symptoms for ASD. In that situation, it falls under the need of medical necessity and medical health needs.

SENATOR STEINBERG: Thank you very much. Thank you, thank you. Please.

DR. ROBIN HANSEN: Thank you for inviting me, Senator Steinberg, Members of the Senate Select Committee on Autism and Related Disorder, distinguished colleagues, and families, and others present in the audience.

SENATOR STEINBERG: You're Dr. Hansen?

DR. HANSEN: I'm Dr. Hansen, and I've been asked to follow Dr. Amaral and Dr. Rogers by addressing the question: What is the evidence for medical treatment of ASD?

The evidence-based practice of medicine is generally defined as the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of the individual patient. The evidence base for determining medical interventions is increasingly driving decisions about healthcare expenditures. The three main components of evidence-based medicine that need to be integrated in clinical decision making to maximize individual outcomes for any medical treatment include clinical expertise, patient values, and the best evidence from clinically relevant and methodologically sound research.

The critical evaluation of existing research related to the strength of evidence, either supporting or refuting treatments, relies on determining that scientifically rigorous methodology has been used, that safety has been monitored, and that the findings have been independently replicated. Generally, the strongest level of evidence includes systematic reviews and meta-analyses of randomized controlled trials in which ideally both the patient and the treating professional are "blind" to who is receiving treatment and who is receiving placebo. This is followed by well-designed but nonrandomized case-controlled or uncontrolled cohort studies where everyone knows who's being treated, and then the lowest level of evidence would be descriptive case reports. Unfortunately, at this point in our knowledge, the majority of our treatments that are traditionally considered medical are descriptive for ASD, and many treatments that initially seem very promising lose their apparent efficacy as they're subjected to higher levels of scientific rigor.

Over the past several decades, however, the evidence base for treatment of ASD has been growing in both quality and in quantity. Three major systematic reviews were recently completed that extensively reviewed and rated the evidence base for treatments, addressing both core and associated symptoms of ASD. These include the National Professional Development

Center on ASD, the National Standards Project, and the IMPAQ ASD Services report for the Centers for Medicare and Medicaid Services. The California Department of Developmental Services has also nearly completed their own similar evidence-based review to try and establish guidelines for best practice for ASD treatment. There's been an increasing amount of very strong evidence to support a variety of behavioral interventions that effectively treat the core social and communication deficits in individuals with ASD, the fundamentals of which are described by Dr. Rogers.

At this point, the evidence base for which we have traditionally considered medical treatments is much more limited in terms of successfully treating the core symptoms of ASD. At present, there's no drug or other biomedical treatment that has consistently been proven to be effective in directly treating these core symptoms.

There is much stronger evidence, however, supporting medical treatment of associated symptoms common in children with ASD, such as inattention, impulsivity, hyperactivity, irritability, gastrointestinal symptoms, and sleep problems. Studies have shown that up to 50 percent of children and adolescents with ASD are on psychotropic medications, despite a paucity of high quality evidence for most of this treatment, and much of this use is largely off label.

There are only two medications that have been approved by the FDA for use specifically in autism to treat irritability. When irritability is effectively treated, social interactions and communication may also improve secondarily. However, there are significant side effects that are associated with many of these treatments, and the benefit/risk ratio for treatment must be considered for each individual. We also do not have longitudinal data on the effect of long-term use of psychoactive medication on children, particularly during the time of very rapid brain development. And as we're trying to do much better early identification and early treatment, this becomes a very important consideration in the treatment, the medical treatment, as it exists now and has been defined for medical coverage. So the preponderance of evidence for effective treatment

of the core symptoms of ASD largely supports behavioral interventions, such as those described by Dr. Rogers, and the developmental mechanisms for changing brain structure and function described by Dr. Amaral.

There are many promising clinical trials underway at the MIND Institute, nationally and internationally, that are evaluating new medical treatments for ASD. But until we have a better understanding of the underlying etiologies and specific neurobiological targets for medical treatment, what is currently considered medical treatment of core symptoms of ASD is very limited and should be considered adjunctive treatment to the individualized behavioral and educational interventions that have a much stronger evidence base for effective treatment of the core symptoms of ASD. Thank you.

SENATOR STEINBERG: Thank you.

Are there questions by the panel for anyone?

Again, your focus here is on target symptoms, target symptoms, in terms of drawing the imperfect line between what is educational in nature and what is medical in nature, correct?

DR. ROGERS: The best way I thought of, I've come up with so far.

SENATOR STEINBERG: And I know we'll hear from others throughout the course of the morning, but what is the general point of view from others on using that methodology to make that determination?

DR. ROGERS: You know, I haven't heard other people talk about this actually. I simply have not heard this question addressed outside of our state in the last six months or so that this dialog's been going on. So maybe people in the audience have an answer to that but I don't.

SENATOR ALQUIST: I do have a question.

SENATOR STEINBERG: Yes, Senator Alquist.

SENATOR ALQUIST: A question. Is there disagreement among the medical and scientific community about the value or efficacy of ABA therapy, and is there any evidence that is not of great value? In other words, are you all in alignment saying this is the way to go, or are there people amongst you who would disagree in the scientific and medical community?

DR. ROGERS: The empirical evidence is overwhelming of the effectiveness of behavior therapy for autism.

SENATOR ALQUIST: Thank you.

SENATOR STEINBERG: And we actually do not have a panel here of educators or administrators who do IEPs that are involved in special education. What views, if you know, have they expressed about the IEPs? What is the practice of the IEPs including, or not including, ABA therapy?

DR. ROGERS: Well, the IEP specifies the skill that the child is to acquire. So learning to recognize names, learning to recognize numbers. ABA is a procedure for teaching. It's not a target symptom itself. IEPs don't specify what teaching procedures should be used. IEPs specify what skills are to be acquired by the child.

SENATOR STEINBERG: But in the end, the school district does make a determination, often in cooperation, sometimes in conflict, with the parents about what services will be provided to address the needs of the child. Do you know of IEPs that include the actual provision or the end result being the provision of ABA therapy under the IEP?

DR. ROGERS: You know, I don't feel like I can answer that question well for you. There may be other people.

SENATOR STEINBERG: Okay. That's certainly another question out there for other panelists to be able to address.

Senator Alquist.

SENATOR ALQUIST: Both as a former school counselor and then back when I was in the Assembly attending with one of my parents an IEP meeting, how equipped do you think the school—and I know this is a hard question; you may not want to touch it but at least I just wanted to put it out there—how well equipped are our public schools to do the kind of treatment that would benefit children with autism, with the syndrome, spectrum, rather?

DR. ROGERS: Well, school staff, special-education school staff, include behavior analysts, psychologists, special educators, speech pathologists—all these people—people who are specializing in serving young children with

developmental disabilities—have learned these techniques as part of their training. The use of behavioral approaches to teach children with disabilities has a very long history. However, nationally we're recognizing, that as more and more children are diagnosed, this puts a great demand on public schools to increase the knowledge of school staff to use these effective techniques, and there are a number of projects going on nationally to increase the schools.

In our own state, we have a project Dr. Hansen and I are working together on, on the National Professional Development Center's work, which is a national group focused on enhancing public school skills to serve children with autism, and we have a large project right now going on in the state of California with individual classrooms which are enhancing teaching staff's ability to use behavior therapy approaches with empirically supported practices to teach children standard educational curriculum.

SENATOR ALQUIST: And on that point and just very briefly, because I know it's a long hearing, but rather than just pilot-type projects, how does the medical and scientific communities come together with the education community on a broad basis to see that all children who have autism have the best available therapies to them while in the public schools?

SENATOR STEINBERG: I think that is *the* question for the hearing. I mean, I know it was asked specifically but it's also rhetorical and that's exactly what we want to explore here and I'm not sure these witnesses necessarily...

SENATOR ALQUIST: Right. I know. I ask unfair questions.

SENATOR STEINBERG: ...are the ones to answer it. No, but it's absolutely the right question. Of course, the one thing we need to point out about the IEP in the education system is that that doesn't address kids who are not yet in school.

SENATOR ALQUIST: True.

SENATOR STEINBERG: It's only when the child gets to kindergarten.

Okay. I want to say thank you very, very much.

UNIDENTIFIED SPEAKER: Preschool.

SENATOR STEINBERG: Well, there's preschool too.

DR. ROGERS: You get an IEP in preschool.

SENATOR STEINBERG: You get an IEP. Thank you.

DR. ROGERS: Thank you.

SENATOR STEINBERG: Thank you.

Next, we want to get right into the regulatory framework for private insurance coverage of ASD services, and the folks who are responsible for making the current interpretations under the law, of course, is the State Department of Managed Health Care and the Department of Insurance.

We have a couple of qualified representatives here to talk about this issue. Rick Martin is the deputy director for Plan and Provider Relations from DMHC. Welcome. He's not here. Well, I take back my welcome. (Laughter) Holly Pearson, welcome, general council DMHC; Andrew George, assistant deputy director of Help Center, DMHC; Tim LeBas who's the assistant deputy director, Office of Legal Services, DMHC; and Elena Fishman from the Department of Insurance.

Why don't we begin with Ms. Pearson here. And obviously the question here is: You're the regulator; you're called upon to make determinations in individual cases and interpretations. How do you view this issue of ABA therapy and the responsibility of health providers to provide this service?

MS. HOLLY PEARSON: Let me step back a bit and say plans are required under the Knox-Keene Act...

SENATOR STEINBERG: Gotta get your mike. There you go.

MS. PEARSON: Too far?

SENATOR ALQUIST: The red light should be on.

SENATOR STEINBERG: The red light.

MS. PEARSON: Thank you. Under the Knox-Keene Act, which is the body of law, the department enforces, health plans are required to provide healthcare services. So this premise is evidence throughout the Knox-Keene Act. They are required to provide basic healthcare services. The definition of benefits and coverage says that they are required—those benefits are the healthcare services that are stated in the health plan contract.

Now health plans, as you know, sometimes deny ABA on the grounds that it is not a healthcare service. Now the Knox-Keene Act does say that licensed providers by the state are the only people who can actually provide healthcare services. So when plans deny ABA on the ground that it is not a healthcare service, we then have to make a legal determination as to whether that service is covered under the health plan contract; and the way we make that legal determination is looking at the Business and Professions Code's requirements that say only people who are licensed or recognized by the Business and Professions Code to provide, to treat medical and mental conditions, can actually provide those services or somebody who is accepted or recognized by the legislature not having to hold the license. So if an enrollee submits or their treating provider submits a document or prescribes ABA therapy for that enrollee because it is medically necessary and that treating provider also says, that because of the enrollee's condition, the services must be provided by the licensed provider, then the department finds that it is a covered service, and then we go to the plans and say, plan, you must now provide this service. But the plans have the option of either providing the service or then denying the service on the grounds of medical necessity. If the latter, we then send it to IMR for clinical determination of whether the service is actually medically necessary for that enrollee's condition.

SENATOR STEINBERG: It's all about, it's really all about the provider, is what you're saying. The department has not rendered a sort of a scientific opinion about whether or not the symptoms being treated are more medical related than education related?

MS. PEARSON: We are not clinicians. The test, you know—again, plans are required to provide healthcare services. Our line of demarcation of what is a healthcare service versus something else—whether it's educational, social, whatever the case is, Does the enrollee's provider state or believe that that ABA or the service, because of the level of the enrollee's deficits, must it be provided by a professional recognized by the legislature as providing that service? So, yes, the response to your question is, we do not necessarily look at the

symptoms of the enrollee other than—you know, as part of the process of resolving an enrollee's complaint, we do ask that the enrollee submit a treatment plan from their provider, and the reason we do that is, we need to understand exactly what services is being requested by the enrollee.

Now, you know, we can't really go much further than that because we don't have the clinical expertise and then we would be entering into, is this a medical necessity determination? What we are looking at is coverage, which is just a legal determination.

SENATOR STEINBERG: Senator Alquist?

SENATOR ALQUIST: Thank you.

I think a lot of times what happens up here is that certain things don't get done because we don't agree on terminology on definition. And so what I'm asking is, Is there an agreed-upon definition of, first of all, the ABA therapies but also an agreed definition of what must be done for the consumer, what must be done for the autistic child? I mean, do we all agree so that a parent knows what to do and that it will be accomplished?

MR. ANDREW GEORGE: Well, again, I think what we're indicating is, what we're in agreement to or what is required to the provider is within the Knox-Keene Act, and that's essentially what is defined as healthcare services.

SENATOR ALQUIST: But hasn't that also changed through the years, of our expectations of scientific evidence, empirical research? So what I'm asking too is, maybe some things need to be done a little differently—we need new terminology. I don't know if it's new legislation. I don't know what it is but something that allows for these kinds of therapies on a regular basis, 100 percent of the time, to be provided.

SENATOR STEINBERG: This may be—that's right. There may need to be some clarification. That's part of what we want to understand from you, is certainly your suggestions and recommendations as to what might provide more clarity. For example, could you give me a 30-second refresher here on the Knox-Keene Act and the Business and Professions Code, what provides are included within the B&P Code? Is it just physicians or is it...

MS. PEARSON: Absolutely not.

SENATOR STEINBERG: Remind us, please.

MS. PEARSON: I'm sorry. There's a laundry list of providers in the B&P Code. There could be licensed psychologists; there could be licensed marriage and family therapists, clinical license, clinical social workers, but also, you know, the B&P Code does include unlicensed people. However, they are usually assistants, medical assistants, or people who are undergoing a course of study and working towards...

SENATOR STEINBERG: So who has to provide the authorization for you to determine that the therapy, the ABA therapy, is medically necessary? Who do you need the letter from?

MS. PEARSON: The enrollee's treating provider or referring provider.

SENATOR STEINBERG: Treating provider. You didn't say treating physician.

MS. PEARSON: No.

SENATOR STEINBERG: You said treating provider.

MS. PEARSON: Absolutely, yes.

SENATOR STEINBERG: So if a child is receiving services from a regional center, from a private provider—a speech therapist—that therapist can certify that this therapy is medically necessary—a non-physician can certify that this is medically necessary—and you will, writ large here?—a legal term.

MS. PEARSON: We're all lawyers. (Laughter)

SENATOR STEINBERG: You will approve that authorization or say that that authorization is necessary?

MR. GEORGE: Well, I think to clarify, I think what the statement is, Does that particular child's deficits require the skills and expertise of a licensed provider? And if so, we're making the determination then, that based upon that representation, it is a healthcare service and a healthcare service are what are covered services.

SENATOR STEINBERG: But I want to understand your degree of analysis here because a social worker could, and I'm sure does, write, not as

any kind of a scam or anything like that, but a treating social worker could write a letter—and I'm sure they do every day—saying this therapy is medically necessary and here are the goals it seeks to achieve for this child and here are the benchmarks, and we're trying to understand whether or not you go behind the four corners of that kind of letter or declaration from a provider, a non-physician provider, and approve or ask more questions.

Is the question making sense?

MS. PEARSON: Yes, absolutely.

MR. GEORGE: Andrew George, assistant deputy director of the Help Center. It's a very good question. I think at the end of the day, we're just deferring to, by and large, to the clinical expertise of the provider. We do not have the expertise to make that distinction between, say, what might be educational versus what is medical. So again, at the end of the day, what I want to make clear of, is that we're not determining the ultimate issue of medical necessity with respect to the questions that you're referring to but really trying to get at the underlying determination of, Is this a covered healthcare service? So we wouldn't—we're not relying upon a representation in that context as to the ultimate issue of medical necessity but trying to make the threshold determination of coverage. But we have determined that we need to rely upon the clinical expertise of the person that's making that assessment, that's treating the child. Again, it's only as it relates to a covered healthcare service.

SENATOR STEINBERG: Well, it begs the question for me—and maybe for others as well—we'll hear from the consumers and from others—of what's the problem here? In other words, what is the real-life challenge here to accessing the service and ensuring that it's covered because you're certainly suggesting a pathway here. The medical community—I don't want to overstate this. The autism advocacy community, which includes providers, physicians, and other providers, believe very strongly that this is a medical service. And what you're saying here is, that if they assert that on behalf of a child, that by

and large, so long as it's asserted in an appropriate and effective way, that you will not, you're not making a medical judgment, you will approve that, correct?

MR. GEORGE: Yeah, we are making the determination based upon...

SENATOR STEINBERG: Okay. Go ahead. Sorry.

MR. GEORGE: Again, we're making a determination based upon the representation from that provider, is that the child's, you know, deficits require the skills and expertise of a licensed provider.

SENATOR STEINBERG: The providers can include licensed clinical social workers, MSWs...

MR. TIM LeBAS: Psychologists.

SENATOR STEINBERG: Psychologists, et cetera. Okay. So...

MR. GEORGE: Based upon that determination, we are concluding that then it is a healthcare service and healthcare services are what are required to be covered pursuant to the act.

SENATOR STEINBERG: You seek—and I don't know if you're authorized here because I know the department is part of the administration; but authorized or not, can you give us any guidance here as to whether or not we ought to consider legislative clarification here that would make it easier for you to do your jobs?

MR. LeBAS: Mr. Chair, Tim LeBas. While we can't comment on policy suggestions and legislation without proper authority, as you know, I would like to at least make this notation of current law under the Business and Professions Code, which goes to Dr. Rogers' comments about differentiating symptoms, for example, educational versus non-educational.

There is in the Business and Professions Code a distinction between a psychologist who directly provides health and mental health services and an educational psychologist who provides services in relation to academic learning processes, which some of the examples were given earlier by the first panel. So to answer your question based on existing law, the distinction may have been started at least with respect to one licensee in that area.

SENATOR ALQUIST: I have two questions.

The first one is, what types of services are typically denied by plans, and what are the bases for those denials?

The second question, separate from that is, I think a lot of these—I'm told a lot of these—cases go to independent medical review, and my question is, How are those who do this review, how are they are trained in the latest therapies? How much do they know?

MR. GEORGE: Well, to answer your first question, the denials that we would typically see again are for ABA therapy. And again, the basis for denials range, but typically again, the argument is that ABA is an educational, is an educational...

SENATOR ALQUIST: It seems to be the crux of the hearing, yes.

MR. GEORGE: Absolutely.

SENATOR ALQUIST: Okay.

MR. GEORGE: As opposed to a medical service. Some might still be asserting the denial, although it's rare now that it's experimental, investigational. But the more typical denial is that ABA is being denied on the basis that it's an educational service, not a healthcare service.

SENATOR ALQUIST: And so when it goes to independent medical review, if people are trained to think that it's educational and not medical, then they're certainly rejected.

MR. GEORGE: That has not typically been the case with respect to the independent medical reviews.

SENATOR ALQUIST: Well, that's good. So what is the percentage on the independent medical review of it being approved on a medical basis?

MR. GEORGE: Since the beginning of the IMR process—again, this is going back, to say, 2001—I believe we've had roughly 33 independent medical reviews for ABA and a vast majority of those who've come back, the denial is overturned somewhere, you know, close to...

SENATOR ALQUIST: So that's a positive?

MR. GEORGE: Right. And more recently, again, as the science has developed, more recently those decisions are coming back consistently overturned in favor of the member.

SENATOR ALQUIST: So as the science is being promulgated, as people are being educated to understand the benefit of the ABA therapy, more often than not, these cases are approved? So this speaks to partially—I'm sorry to interrupt you.

MR. GEORGE: That's okay.

SENATOR ALQUIST: I'm 65, you know, and I could forget what I was going to say here. (Laughter) But that speaks to saying that the evidence, that the scientific evidence, in support of ABA therapies is really widespread so that everybody is educated so that these therapies are more often approved for the children?

MR. GEORGE: Again, I'm not a clinician, so I couldn't be prepared to comment on that.

SENATOR ALQUIST: Well, that's just sort of a late question. I mean, logically speaking, if everyone understands that the ABA therapies work, there's a better chance that it will be approved to be used for children. To me, that's more of a logical—but you may not want to comment at this time. Okay.

MR. GEORGE: As a non-clinician, that's not for me to comment on.

SENATOR ALQUIST: Okay. Thank you.

SENATOR STEINBERG: I'm a little slow. I'm trying to understand the issue here. It sounds like your view of the Knox-Keene Act and the Business and Professions Code and how it applies to this ABA therapy is actually fairly clear. You talk about the vast majority of independent medical reviews—and there only have been 33 in God knows how many cases—it seems a rather small number—but you've overwhelmingly overturned the denial. You've told us, that if the request is framed appropriately as a professional under the B&P Codes saying that ABA is medically necessary, that if it gets to you, your interpretation is that it should be covered. It sounds like, though, the issue is that there are many cases that don't get to you.

SENATOR ALQUIST: Yes.

SENATOR STEINBERG: And that's what we're going to hear from, I think, the consumers.

So have you engaged in, for example, a rulemaking process under the Administrative Procedures Act to clarify this in more of a policy construct as opposed to, you know, as opposed to being just an appellate body? Because we know, you know, with administrative agencies and with the courts that not everybody, whether it's affordability or knowledge, is going to access an appeal. So what has been the deliberation about actually putting out a policy statement here, either through rulemaking or otherwise, to clarify what is your pretty obvious interpretation of the Knox-Keene law and the Business and Professions Code?

MR. LeBAS: Mr. Chair, Tim LeBas again.

Back on March 9, 2009, the department did issue a letter, all-plan letter, which we believe confirms existing law, including the license provider issue. There are some who have taken exception with that letter. There's a current lawsuit ongoing with the department that, of course, we can't comment on. But once that issue is resolved through the judicial forum, we obviously will reevaluate the need for regulations.

SENATOR STEINBERG: A letter, though, itself, is not binding. I mean, it's essentially an advisory opinion, correct?

MR. LeBAS: Well, this letter was a confirmation and an educational tool reminding health plans their obligations under the Knox-Keene Act to provide services in accordance with the law.

MS. PEARSON: Yes, Mr. Chair, you're quite right. Really, it was just a restatement of existing law and reminding health plans of their requirements under the act to diagnose and provide treatment to autistic children.

SENATOR STEINBERG: What did the letter say specifically say about ABA?

MS. PEARSON: The letter didn't mention ABA, I don't believe. It simply said you cannot categorically exclude any specific service for mental health conditions.

SENATOR STEINBERG: The basis for the letter was the Mental Health Parity law or Knox-Keene?

MS. PEARSON: The entire Knox-Keene Act.

SENATOR STEINBERG: Okay.

MS. PEARSON: So we pulled—so it's just a restatement of plans, obligations under existing law in the Knox-Keene Act which includes the Parity Act, yes.

SENATOR STEINBERG: All right. Any other questions from members of the panel?

Let's hear from the Department of Insurance—I'm sorry, Ms. Fishman. Welcome to you.

MS. ELENA FISHMAN: Thank you. Good morning, Senator Steinberg, Committee Members, and participants. My name is Elena Fishman and I'm a senior staff counsel with the California Department of Insurance.

First, we'd like to thank you on behalf of Insurance Commissioner Poizner for inviting us to participate in this hearing on a topic of great importance to families in California.

My testimony this morning has developed in collaboration with Leone Tiffany who is the chief of our Consumer Services Division that oversees our IMR process and Andrea Rosen who is our lead health enforcement attorney.

The Department of Insurance licenses, monitors, and regulates health insurance companies. These health insurance companies sell PPO, preferred provider health insurance policies. And health insurance is defined in the Insurance Code in detail in Section 106.

The first question that was posed to us is, How does the Department of Insurance monitor health insurer compliance with the Mental Health Parity Act for Autism Spectrum Disorder? Our complaint-handling process of our Consumer Services Division and our Consumer Hotline are the key methods for

monitoring health insurer compliance. All consumer complaints received with a denial of ASD services are handled with the goal of obtaining a fair resolution by providing an independent review of the insured's coverage in the medical necessity of the services recommended. The department communicates with both the insured and the insurer to obtain resolution. Additionally, during our review process, a regulatory review is performed to determine whether the insurer has violated any insurance codes, statutes, or regulations.

In 1999, the legislature enacted Insurance Code Section 10169 which established an independent review system within the department to handle grievances involving disputed healthcare services. Consumers or their providers may request an IMR when benefits have been denied. Additionally, complaints received by the department may be eligible for the IMR program, and those complaints are then segregated and the insured is notified of the IMR program, explained what it's about, how it operates, and encouraged to participate.

The department also publishes information on the IMR program on our website and apprises consumers of the program through both our toll-free consumer hotline and also the hundreds of outreach events that the department staff participate in throughout the state. When an IMR request involving a denial of behavior intervention therapy or applied behavioral analysis for an insured with ASD is received, the complaint is reviewed by department staff to determine eligibility for our IMR program.

The focus of the review centers on four things. First, was the treatment recommended by a licensed physician; second, was supporting documentation received from the insurer or the provider; three, was the asserted basis or reason for the insurer's denial or limitation of the service and any supporting document provided; and four, does the case involve potential questions of medical necessity or experimental investigational services? After all this information is reviewed, a determination is made as to whether the complaint is eligible for our IMR process. And if so, it goes through the IMR review process.

The second question that we were asked to comment on is, What are the criteria we use to determine if behavioral ____ therapy is a covered benefit and whether it qualifies as a medically necessary service for ASD? Since the department's staff are not physicians or licensed medical practitioners, it's not within our scope of our expertise to make any of those determinations as to whether the recommended service is medically necessary or experimental, investigational in nature.

In accordance with our Insurance Code Sections 10145.3, 10169, which are attached in the handout that I prepared for you, if there is any experimental or investigational treatment or potential medical necessity issue involved in the denied claim or service, including ABA treatment, the department utilizes the IMR process to make the final determination. IMR panel determinations are then adopted by the department and are binding on the insurer, and it's very important to remember that the department is the final arbiter when there is a question as to whether an insured's grievance is a disputed healthcare service or a coverage decision. If there appears to be any potential medical necessity issue, the grievance must be resolved through our IMR process. However, the IMR process is not available for coverage decisions.

As a final note, the number of ASD cases that are coming to our attention is relatively small. In 2009, the department sent three cases in which ABA treatment was denied to our IMR process. In all those three cases, they were overturned in favor of the insured. And in 2010 through the month of April, we've sent two cases through the IMR process in which ABA treatment was denied, and both of those cases have been overturned in favor of the insured as well. One of the issues that we are definitely looking at is how to get information about our IMR process to the consumers and to the families to make sure that they know that this is available to them.

Thank you very much, Senator, and Committee Members for having us.

SENATOR STEINBERG: I appreciate your coming and informing us. I do need to ask—I'm sorry, Senator Pavley. Go ahead.

SENATOR FRAN PAVLEY: For point of clarification.

SENATOR STEINBERG: Go ahead.

SENATOR PAVLEY: How many cases have been approved?

MS. FISHMAN: Well...

SENATOR PAVLEY: You mentioned two denied in April and three denied last year.

MS. FISHMAN: I don't have those statistics and I'm not sure we actually collect statistics on how many cases are approved because we wouldn't know about them. They wouldn't come to our attention if a health insurer has approved the request for services.

SENATOR PAVLEY: But you denied the appeals, correct?

MS. FISHMAN: These are cases that the insurer has denied the service. They've denied paying for it. They've come to us, gone through our appeal process, and had been overturned during the appeal process, so we had two so far through April this year and three in 2009.

SENATOR PAVLEY: I needed a definition for medical necessity.

MS. FISHMAN: I don't...

SENATOR PAVLEY: Your point of view. Maybe you could just describe that for me.

MS. FISHMAN: I don't have that information, but that is definitely something that our department experts, who unfortunately are in trial this week, would be able to provide you. I'd be happy to get that to you.

SENATOR PAVLEY: Thank you.

SENATOR STEINBERG: Thank you. So I want to press a little harder here with our DMHC leaders here. You've described what I take is a little bit of a back-and-forth process and a dispute about interpretation in a letter that you put out in March 2009, which is now subject to a lawsuit. Ambiguity, of course, breeds lawsuits and the question is, Why wouldn't the department take it upon itself to begin a regulatory process that would clarify the issues that we are discussing here today? Regulatory process under the APA has the benefit of full public input. It's less political, so to speak, compared to the legislative

process. Why is the department leaving this out there in a way that continues this ambiguity?

MR. LeBAS: Mr. Chair, again, the March 9 letter, we feel, is very clear. We feel that it restates existing law.

SENATOR STEINBERG: Excuse me. It doesn't even mention, as you said, ABA therapy.

MR. LeBAS: No, it doesn't.

SENATOR STEINBERG: So that's not clear to me, and I'm not sure it's clear to everybody out there. Go ahead.

MR. LeBAS: Our existing Mental Health Parity Rule in 1300.74.72 provides clarification on the types of services when deemed medically necessary need to be provided by a licensed provider. So the law could argue that it's clear in that area. The letter did not mention ABA therapy. We are handling those cases, though, through the department. And as Assistant Director George indicated, when those go to IMR or other processes for resolution, the bulk of them are resolved in favor of the consumer.

I did want to clarify something for you, though, that you mentioned earlier. It would be a misconception to state, that if we just get a letter, for example, from a provider saying it's needed and it arises to a level of somebody requiring a license, that that's the only thing the department considers. These are difficult cases based on facts, and the department does go beyond the four corners of the document to look at all evidence presented, including the nature, purpose, and circumstances of the services as presented in the treatment plan, for example, and so forth, so that we do resolve and have a fair system for resolving these types of cases.

SENATOR STEINBERG: Okay. Let me go back—33 IMR appeals since when?

MR. GEORGE: Going back to—since the inception of the IMR program, 2001.

SENATOR STEINBERG: Two thousand one. So the past nine years, there have been 33 cases. Do you have any estimate as to how many claims

have been made by consumers to their health plan specifically requesting the ABA therapy? It's got to be in the thousands, right? It's got to be in the thousands. So you've addressed 33 cases directly, or at least through appeal.

The decisions are not precedential ???. They're not embodied in a regulation. So what are the thousands of people out there who are struggling with their insurance company supposed to do here? In other words, I'm frustrated a little bit that the administration, the department, would not take the bull by the horns and clarify the law here. I mean, we can do it legislatively, but I've got to tell you, I'm no expert. I'm certainly not a clinician and I'm not—you know, the legislature, with all due respect to our beloved institution that does a lot of great work—I mean we ought to really be the last people to be drawing these kinds of lines. But you're the experts here. Why not do regulations? One more shot.

MR. LeBAS: You know, the issue under the Knox-Keene Act really deals with, Do we have a licensed provider that is providing this service? Because once you find that and once you find that a health plan contract does allow for these services to be provided, with all the facts before us, the conclusion would be that it would be a covered service. But with that said, whether or not this type of service is within a provider's scope of practice is something the department would not have the ability to provide regulations on. That would be a subject before, for example, another agency, such as the Department of Consumer Affairs. So while we do make determinations on whether or not the service is a covered service—including whether or not that service is being provided by a licensed provider—whether or not that service rises to the level of requiring a licensed provider is in another law and is it within the scope-of-practice issues that are before the Business and Professions Code.

SENATOR STEINBERG: I do have one last question from Dr. Vismara. Do you view ABA therapy in the abstract, regardless of the provider, to be an education benefit or medical benefit? I mean, primarily of medical in nature or education in nature?

MR. GEORGE: Again, I think that that's just the issue that we're grappling with and, unfortunately again, don't have the clinical expertise to resolve. So again, we have to go back to the Knox-Keene Act for our resolution and we have to deal with it within the parameters of the Knox-Keene Act. The Knox-Keene Act talks about providing healthcare services, and that's the determination that we're trying to make.

SENATOR STEINBERG: Very good. Thank you very much. I appreciate your testimony, everybody. Thank you.

Okay. (Gap in hearing from 01:17:05 through 01:17:23)

Now we move to the panel, the Health Plans' Perspective, obviously very important. We want to welcome former Senator Patrick Johnston, president and CEO of the California Association of Health Plans; David Ormerod, M.D., the medical director of Blue Shield of California; Dr. Dan Mordecai, the director of Mental Health and Chemical Dependency Services, Kaiser Permanente, Northern California; and Sandra Gloze—did I pronounce that correct?

MS. SANDRA GOLZE: Golze.

SENATOR STEINBERG: Golze. I apologize. Sandra Golze, the vice-president and regional counsel for the Northern California Region of Kaiser Foundation Health Plan, Incorporated, and Kaiser Foundation Hospitals; and...

MS. MARY POWERS ANTOINE: I'm Mary Antoine with Nossaman, legal counsel to California Association of Health Plans.

SENATOR STEINBERG: Okay. Welcome to you.

Senator Johnston, tell us about the Delta. No, wrong hearing. (Laughter) Wrong hearing, sorry. Go ahead. Welcome to you.

SENATOR PATRICK JOHNSTON: No less controversial.

SENATOR STEINBERG: No less controversial.

SENATOR JOHNSTON: Thank you, Mr. Chairman and Members. I'm Patrick Johnston, president of the California Association of Health Plans. We appreciate the opportunity to testify at this hearing on autism insurance coverage.

I know that the loving families of children with autism seek assistance from many sources, including schools, government, and their health insurers. Your Blue Ribbon Report identified the challenges, the gaps, and certainties and needs. Today our panel will address the legal and medical questions that the committee has posed to us.

California health plans provide comprehensive coverage for autism-related healthcare services, including diagnosis, assessment, medication, and speech, physical, and occupational therapies, as well as psychotherapy for the individual and family. They do so every day. Educational services and behavioral skills training, whether provided by licensed or unlicensed persons, historically and appropriately have been offered by regional centers and schools. We follow the law. We have to do our part. Society and the public sector must do theirs.

I'd like to just briefly, Mr. Chairman, review how we got here as a matter of law. In 1975, Assemblymember Jack Knox and Senator Barry Keene authored the law that bears their names. It's a comprehensive statute that requires a full-service health plan to provide all of the basic healthcare services including hospital inpatient services, physician services, and ambulatory care. The full law has some others, including preventive care and hospice care. In 1999, Assemblymember Helen Thompson and Senator Don Perata authored the Mental Health Parity Act. The chaptered version of AB 88 reads: "Every healthcare service plan contract that provides hospital, medical, or surgical coverage shall provide coverage for the diagnosis and medically necessary treatment of severe mental illnesses of a person of any age and of serious emotional disturbances of a child under the same conditions and terms applied to other medical conditions—one, maximum lifetime benefits; two, co-payments; three, individual and family deductibles."

What problem did the legislature seek to address in 1999? It was the unequal treatment of severe mental illnesses by insurers in the application of lifetime limits, co-payments, and deductibles for medical services. What

medical services? The law says the same ones that always apply to physical conditions.

What did AB 88 not do? It did not move the line; it did not require new medical services, as a matter of law, like prescription drugs, and it did not require non-medical services. Medical treatment services are inside the line. Health plans cover them. Educational and behavioral training services are outside the line. Health plans do not cover them unless and until, unless and until, the legislature changes the law. But the law, the one, Mr. Chairman, that you and Senator Alquist and I voted for, has not changed.

SENATOR STEINBERG: Let me ask you...

SENATOR JOHNSTON: Yes, sure.

SENATOR STEINBERG: If you don't mind, Senator Johnston, because you've used the term *behavioral training services* a couple of times as sort of the line of demarcation, I think, that Mental Health Parity does not cover behavioral training services. And one of the doctors in the first panel talked about basing the determination, if you will, on what target symptom the providers are trying to treat. And so I know you are not a doctor, neither am I, but is the inability of a five-year-old child to not speak, to not speak, a behavioral training service? Is that behavioral?

SENATOR JOHNSTON: Medical questions, I'd like to direct to our medical witnesses.

SENATOR STEINBERG: Fair enough.

SENATOR JOHNSTON: I think the point that Senator—excuse me—Senator Alquist said, you know, that in fact expectations change, expectations change, and regulatory agencies respond or courts sometimes get involved. Legislature hearings engage the issues because research occurs and more is learned. Health plans follow the law and the law has not changed. That's within the purview of this body to consider. So as long as the law makes the distinctions that it does and requires the services that it does, health plans have the expertise and the duty to provide those. So perhaps this is a good point to segue to the doctors and to address your question.

SENATOR STEINBERG: Yes.

SENATOR JOHNSTON: Because I heard that very interesting testimony about target symptoms.

SENATOR STEINBERG: And it'll spark a good conversation here. Go ahead.

DR. DAVID J. ORMEROD: Good morning, Mr. Chairman and Committee Members. It's my pleasure to represent Blue Shield of California during this important dialog on autism treatment. As mentioned, I'm Dr. Dave Ormerod, senior medical director for Blue Shield. Prior to Blue Shield, I was the medical director of clinical research management for UC Davis Health System; and prior to that, I was in full-time family medicine practice.

As a clinician, I've treated patients and families impacted with Autism Spectrum Disorder and can fully empathize with and understand the challenges that these families and individuals must face on a daily basis. We have thousands of Blue Shield members affected by this condition and fully support all efforts to understand what it means to have an autistic child and what can be done to improve their lives. I would like to outline the breadth of services that we do provide to autistic children to support the medical needs of the individuals to facilitate the establishment of the diagnosis and to treat various symptoms of this disease spectrum.

For example, we do cover medical evaluations of these patients, which may include genetic testing and genetic counseling. We cover psychological testing, counseling, psychiatric services. We cover speech therapy services, including language assessment, standardized testing, and corrective and/or adaptive speech therapy treatment. We cover physical therapy, including assessment of functioning by the licensed physical therapist and therapy to address functional deficits in movement, strength, gross, or fine motor skills. We cover occupational therapy which includes an assessment of functioning and therapy to develop specific motor skills which will assist in completing activities of daily living, and we cover audiometric examinations to determine hearing functions and comprehension capabilities.

There are other important non-medical services that are covered that are offered to improve the functioning of autistic children. These include educational services aimed at improving a child's ability to learn or improve their knowledge or skills, and behavioral services meant to improve social behaviors and general functioning, such as learning how to dress themselves. Although these services may be indirectly or directly related to the spectrum of ASD, they do not fall within the classification of medical services and thus are not covered under a health service plan.

As a physician, I understand and have dealt with the impacts of this condition on children and their families, just as so many other innocent individuals are impacted by other medical conditions by non-medical, unforeseen circumstance, or even by natural disaster. However, there is a logical, clinical delineation between what should or should not be covered, health service within a healthcare policy.

We will continue to support all of our members, including children with autism, in accessing medical services for the evaluation and treatment of their conditions. We expect to continue to do so only for medical services, for all of our members, with all medical conditions.

SENATOR STEINBERG: I've got a basic question for you. What is neuropsychiatry and neuropsychology? What is it?

DR. ORMEROD: Neuropsychology would be...

SENATOR STEINBERG: To the layperson out there, what is it?

DR. ORMEROD: The study of the nervous system as it relates to behavior and cognition thinking.

SENATOR STEINBERG: And what is sort of the accepted point of view about the relationship between the physical nervous system and behavior?

DR. ORMEROD: Well, I think the accepted standard is that there is a direct link between behavior and the nervous system. They are linked together.

SENATOR STEINBERG: Wasn't that part of the, as you know, the history, wasn't that part of the impetus for Mental Health Parity at both the state and the federal level?

DR. ORMEROD: I didn't participate in that so I don't know.

SENATOR STEINBERG: Okay. Thank you. Next.

MS. SANDRA GOLZE: Good morning. I'm Sandy GOLZE. Thank you for giving me the opportunity to talk about this.

SENATOR STEINBERG: Of course.

MS. GOLZE: I'm going to cover two topics—the law about the distinction between healthcare services and non-healthcare services, and the impact of the California Mental Health Parity Act on this distinction.

As you know, the law licenses health plans or health insurers to cover or pay for healthcare or medical expenses. The law does list different kinds of provider services that we are required to have available, but it doesn't have any further definition of what is healthcare and what isn't healthcare, and there have always been illnesses, injuries, and diseases that impact an individual's health but also impact learning ability, job opportunities, and the ability to live independently, and these individuals do require special services in their family and school and community so that they can continue to function, and the responsibility for these services has been sorted out and assumed by many rather than calling them all healthcare. That's why there's always been distinctions between healthcare and non-healthcare. This isn't a new issue, and we're challenged to understand this distinction for individuals and families who are impacted by autism.

I'm going to give you some examples of other health conditions where this has been sorted out and where there is a common understanding of the distinction between healthcare and non-healthcare, but first I want to say that this is not my opinion but it's common practice and supported by the regulators. So the first example is deafness and blindness, absolutely a medical condition. But sign language, Braille, speaking skills, school readiness and social skills and the ability to navigate home and community are incredibly beneficial but they're not healthcare.

Another example is Down syndrome, traumatic brain injury, dementia, ADHD. The special educational techniques to help a person who can perceive,

think, problem solve, remember information, and acquire new skills, also incredibly important but not healthcare. Schizophrenia, which is a parity condition, there are special remedial, educational techniques for social development and school workplace skills because, in this case, patients do lose social and occupational functions, and the services to remediate those aren't healthcare. And the next frontier on this is obesity and making the distinctions between healthcare and non-healthcare. The Mental Health Parity Act didn't make any changes to this line. It mandated equal access to healthcare services for individuals with the parity conditions. That's because nothing changed in the general definition of health plans and health insurers when the Mental Health Parity Act was put in.

How do we approach this distinction when services are requested?

First, the health plan has to determine whether the individual requires a healthcare service, and that's the coverage question. Then it can consider whether the service is likely to be the best medical service available. That's the medical necessity question. In the case of an individual where there are learning delays or disabilities, this is the coverage question. Is this about acquisition of skills or knowledge necessary for better functioning in the family community or school, or is it about improving or preventing deterioration in health? And in this, we agree very much with the structure that Dr. Rogers put forth about you have to look at the target symptom rather than who's providing the service. So, for example, services to help a child with ASD family with the symptoms of depression or psychosis or self-injury or using the right muscles to swallow and to vocalize are treatments for mental or physical health and are properly considered healthcare, and we applaud the creators of the programs today that were described earlier. However, we believe that services that foster the acquisition of skills and socialization, communication are properly considered the critical educational services for ASD. They're not medical treatments. And, just like the MIND Institute, we don't believe that the provider's license is the determinator ?? in this.

SENATOR STEINBERG: Ms. GOLZE, so it's very important and interesting testimony. It sparks a lot of questions. But isn't it the case, that with this evidence-based ABA therapy, that it seeks to help on a number of the issue that you just enunciated? In other words, at once it can seek to improve the ability of a child to speak and at the same time have the benefit of helping a child avoid destructive behavior or improve life skills.

MS. GOLZE: So what we do is look at what's being approached, and the part that's about education or life skills, we believe, is educational. It's not about the technique of ABA. It's what it's being used for. So if you get a request for any type of services to approach self-injurious behavior, for instance, we believe that self-injurious behavior is something that is part of mental health treatment. It may not be ABA you use for that. It may be. It may be another technique. But we can't just say, ABA is or isn't healthcare. We have to look at the target that is being approached and then look at the right provider.

SENATOR STEINBERG: But the advocacy community and the scientists, the doctors, the research believe—and I suppose I need—I want to hear your response to this—believe that ABA therapy is the best evidence-based practice for a whole host of these issues—medical and non-medical—that you just described. So it sounds to me—well, I'll let you respond—that you don't necessarily, that the health plans don't necessarily, believe that to be the case or not?

MS. GOLZE: I'm going to defer to the clinician on one portion of it and answer one portion of it because, as to the target symptoms, which we believe are in the educational realm, the fact that there is good research on education is good but it's on education, and we have to be careful that we don't take the word *research* and the fact that it's been done well and that it may be beneficial to help these kids or to educate these kids to make it into healthcare. I believe that our clinicians have varying views on, with a particular child, whether ABA technique or some other technique is better for depression or psychosis.

SENATOR STEINBERG: For what conditions are health plans now approving the use of ABA therapy, Kaiser specifically?

MS. GOLZE: We have approved it once in the case of very...

SENATOR STEINBERG: Please, everybody.

MS. GOLZE: ...a very specific situation where there was extremely self-injurious behavior for a very—for a short period of time where we felt that was the best way at it, at that behavior. You have to look at the behavior.

SENATOR STEINBERG: Okay. You know, this is revealing because I think it is—we can, you know, look at the head of the pin here and make a distinct and argue about the distinction between medical and non-medical services, but there's something different going on here, which is that the health plans don't necessarily believe that ABA therapy is necessary to address whatever it is you're trying to address, either medically, the providers are trying to address, either medically or non-medically. That's really what I'm hearing the issue to be here because the advocates and the researchers are saying, this is top of the line; it's evidence based; it obviously crosses both medical and non-medical lines here. I think that's fairly clear to me because its efficacy is to deal with issues like speech but also with life skills and behavior, and it's either the best practice or it isn't in most cases.

DR. ORMEROD: Senator, I don't think that we want to give the impression that we disagree with the science, that we understand that the standard of the literature of the scientific studies show benefit in cases with ABA. I don't think that that...

SENATOR STEINBERG: Then why not cover the best practice?

DR. ORMEROD: Well, because there are things, Senator, that clearly could be shown by research to be beneficial to people with a myriad of conditions. For example, you know, we brought this earlier, the treatment of obesity could involve a nutritionist who's a licensed clinician, spend every day with a patient for six months with three meals a day and modifying their behavior through techniques to get to them to improve their eating habits. We could also assign a physical therapist to exercise with the patient regularly.

Those are going to benefit—and if a study would show, those services will be beneficial for the obesity, but we would not consider them medically necessary and appropriate.

SENATOR STEINBERG: Well, we're getting to the core of it because with obesity—let's use that as your example—and you used that in my office as well—I could make the argument and you'd make the argument too—that there are much less expensive and equally effective ways to address obesity. I mean, you know, because I just think that's the case.

In this instance, though, when you're talking about a child with autism, you're not presenting the case here—at least I have not heard it—that there are equally effective ways, equally effective ways, to help a child down a path towards success.

DR. DON MORDECAI: Senator, can I jump in?

SENATOR STEINBERG: Yes.

DR. MORDECAI: Okay. I'm Dr. Don Mordecai. I'm the clinical director for Mental Health and Chemical Dependency for Kaiser Permanente, Northern California. I'm actually going to abbreviate my presentation to try to get and get to the questions that you're raising.

Kaiser Permanente did not invent the distinction between medical services and educational services. The care that Kaiser Permanente provides for children with ASDs and other developmental disabilities is consistent with the current policy of the American Academy of Pediatrics, and I want to emphasize that point. That is *the* American body of pediatrics. Essentially it's the premier body for pediatricians and they put out a policy statement entitled *Management of Children with Autism Spectrum Disorders*. And per that policy, we provide medical care and advise parents on potentially beneficial, educational, and other non-medical interventions.

And I want to quote from the policy because I think it really gets at the issue that you're bringing up. So as the American Academy of Pediatrics' policy statement says, "Education is fostering acquisition of skills and knowledge including not only academic learning but also socialization, adaptive skills,

communication, amelioration of interfering behaviors, and generalization of abilities across multiple environments. These services address core features of developmental disorders, including ASDs. We're not disputing that, and we've heard that these services can be very helpful, and we're not disputing that. But the American Academy of Pediatrics—not just Kaiser Permanente, not just Blue Shield—put ABA explicitly under educational services in their policy statement, and that's where our position comes from.

SENATOR STEINBERG: Okay. So that's the foundation of your position. Let me ask it this way—I'm not saying that you have acknowledged this but soon, for the sake of discussion, it's certainly the opinion of many here, that if ABA treatment is the most effective way to address the medical/social needs of children with autism, with many children, with Autism Spectrum Disorder, why is it not a medical necessity under the law? I mean, if it is the most effective, why is it not medically necessary under the law?

MS. GOLZE: When you talk about medical necessity, you're talking about approaching medical issues. You said medical social. There are social and communication issues with autism and there are medical.

SENATOR STEINBERG: Right.

MS. GOLZE: This is a team effort. If there is a best practice in the non-medical field, we feel it should be used in the non-medical field.

SENATOR STEINBERG: But you've acknowledged, at least in part, it's medical as well.

MS. GOLZE: It's part medical.

SENATOR STEINBERG: Speech therapy, speech therapy being the number one example. Dr. Vismara tells me that the vast majority of cases involve speech therapy. That's medical. And even if there are other benefits, which I would sit here not as the expert, acknowledge that it is also social. I'm not saying it's both. But given that part, a large part, of the ABA therapy is intended to address clearly medical issues, why is it not medically necessary?

MS. ANTOINE: Mr. Chair, may I answer that question?

SENATOR STEINBERG: Sure.

MS. ANTOINE: Because I think what your—your statement that a speech therapist is providing this therapy, therefore, it's medical—that's the foundation of what I heard you say. And the fact that a speech therapist may provide certain therapies that others provide doesn't necessarily make it a medical service. There are a number of services that licensed healthcare providers, such as speech therapists, occupational therapists, provide that others who are not licensed healthcare providers also provides. So that is a very important distinction.

SENATOR STEINBERG: That wasn't my hypothetical. It was the speech therapist providing speech therapy, actual speech therapy, in addition to...

MS. ANTOINE: I don't know that that's ABA, sir. I think that the health plans cover speech therapy and that's a required service.

SENATOR STEINBERG: Okay. All right.

Let me ask one more fundamental question. Do you believe from the doctors here the research on ABA therapy, that its consistent application changes brain structure for the better?

DR. MORDECAI: Two points I want to make to that. The brain changes in response to experience fundamentally. That's what the brain does. It's one of the great things about our brains. It changes in response to experience, education, and medical interventions. Just because something is changing the brain does not make it medical. Exercise changes the brain. It's not medical. It's something people choose to do or not.

The other piece I wanted to say is that there's been a lot of talk about, because there's evidence for something, that that should make it medical. There's a whole field of scientific evidence around education, so I think there are certain—we're falling into certain camps, because something has evidence, it must be medical.

SENATOR STEINBERG: Is there a difference between brain structure and brain activity? I know exercise changes brain activity—endorphins and all that stuff and you feel better and all that. But that's different from changing

brain structure. My question is, Do you believe that ABA therapy changes brain structure, the actual structure, of the brain over time?

DR. MORDECAI: I think ABA therapy can change the brain. I'm not sure of the importance of the structure or physiology distinction you're trying to draw.

SENATOR STEINBERG: I don't know that my—well, I don't know. Maybe my brain has changed as a result of exercises. (Laughter) It apparently changes as a result of age.

DR. MORDECAI: Just being here today.

SENATOR STEINBERG: I know that, and it certainly changes as a result of taking this job, I can tell you that. (Laughter) Okay. I won't belabor that.

Last question—I think I know the answer to it but I want to ask whether you agree or disagree with the DHMC interpretation of the law that they described a few moments ago.

MS. ANTOINE: If I may respond to that.

SENATOR STEINBERG: Yes.

MS. ANTOINE: The health plans do disagree with that interpretation. The mere fact that an individual is licensed by the Department of Consumer Affairs under the Business and Professions Code is certainly essential and important for quality control purposes, but it does not necessarily describe whether or not the services that that individual is providing is healthcare versus educational. I think that that is a key disagreement that we have over that issue.

SENATOR STEINBERG: Okay. Thank you very much to the panel. We appreciate it. It was a good discussion.

DR. MORDECAI: Thank you.

SENATOR STEINBERG: Last but not least, we have the challenges faced by the consumers. I know I'm going to have to leave at about ten minutes to 1:00 here, and I know that there's significant public testimony after this panel that I will endeavor to be briefed on and to review, and I know that

there's not another member here currently. So one way or the other, we will make sure—oh, Senator Pavley is back. Good. (Laughter) Just at the right time, Senator Pavley. I just announced that I need to leave at about ten minutes to 1:00.

SENATOR PAVLEY: And I'm catching a flight soon.

SENATOR STEINBERG: You have to leave? Okay. So either way, there will be a full record of the public testimony and we will review it, but let's go to our last panel.

First of all, I want to welcome Feda Almaliti—pronounced that right, I think—cofounder of the ASD Insurance Help Users Group. Again, Dr. Barbara Firestone, Ph.D., and president and CEO of The Help Group—and I said co-chair but vice-chair; I was the chair; I was the chair, okay? (laughter)—Legislative Blue Ribbon Commission; and Lorri Unumb, the senior policy advisor and counsel for Autism Speaks.

Welcome to all of you. So you've heard a lot of testimony today. Well, let's hear the perspective of the consumers.

MS. FEDA ALMALITI: _____.

SENATOR STEINBERG: I think it is. I see the red.

MS. ALMALITI: So my name is Feda Almaliti, and this is my son, Muhammed. I want to tell you Muhammed's story because the story is so similar to the thousands of other children in California with autism. Mohammad was diagnosed by our health provider at 18 months with autism. He doctors recommended many evidence-based treatments for my son and stressed to me the importance of early intervention. On the day of his assessment, I was given a letter by the clinicians. They told me to give it to my regional center. I hadn't even heard of a regional center at that point. They also told me that having the official diagnosis of autism was the key to getting the therapies he needed. I was devastated that he had autism but happy that there were treatments.

While the diagnosis of autism helped him get funding for this treatment from the regional center, I had no idea it would be the death sentence to getting

treatment from my health provider. This was the beginning of our family struggle. They gave me one excuse after another as to why they would not provide treatment for my son. First, they told me to go to the regional center, then the school district. They told me Mohammad's treatment was academic, experimental, custodial, not medically necessary, basically anything but their responsibility. I ultimately appealed their denial through the Department of Managed Health Care and won. After more than a two-year battle, David/Goliath proportions, my son is finally receiving the treatment he needs. I know all too well how this process is literally all consuming and can wreck the lives of families. While our family was lucky, most are not.

I now use my own experiences to help others access medical services through their health insurance companies. I help the families navigate through the maze of securing treatments for autism and have first-hand knowledge of how deliberate and systematically these insurance companies deny the treatment, the services they need.

The problem used to only be the insurance companies. Now it's the insurance companies and the regulatory agencies. Regulatory agencies for families are just as hard to deal with as insurance companies. Families complain of shifting policies. Health plans delay, delay, and deny every single case. Every single case requires an appeal. The Department of Managed Health Care takes forever to determine if the treatment is a covered benefit. Families need to jump through extra hurdles on appeals, and the health plans sometimes just ignore the DHMC's rulings. Most families do not have the ability to navigate this, and there's a general sense that in the case of autism the regulatory agencies are not the patient advocate that they claim to be.

One parent called me sobbing after multiple bad experiences with the regulatory agency, and she said she felt as though she was speaking to an attorney for the health plan. The state in its current budget crisis cannot afford to keep padding the pockets of the insurance companies at the expense of the taxpayers. We must require insurance companies to cover the treatment of autism and ensure the regulatory agencies enforce it. It is the only hope we

have to treat this vast and growing population. It will save the state money—sorry—did you want to ask me a question? Go ahead because I’m ready.

SENATOR STEINBERG: You’re ready. (Laughter)

MS. ALMALITI: I’m not a clinician; I’m not an attorney; I’m a lonely parent, but I’m just going to tell you like it is.

SENATOR STEINBERG: I mean—well first of all, I appreciate you so much, all the parents that take their, you know, own difficult situations and become public advocates because it takes a lot of courage, to me. And I don’t want to be intrusive here in terms of—but given the discussion about medical versus non-medical, you’ve won your case. Would you mind sharing with us what the primary, what the primary issue that the ABA therapy is providing for your son? What is the primary focus?

MS. ALMALITI: Okay. So the primary focus of ABA for my son is to ameliorate the symptoms of his autism.

SENATOR STEINBERG: Okay. More specific.

MS. ALMALITI: More specific. For example, my son could not eat with a spoon or a fork. ABA, along with occupational therapy, helped him do that. My son could not speak. The speech therapy, along with ABA, helped him do that.

SENATOR STEINBERG: Speech therapy along with ABA. I want to focus on the ABA here. The ABA, is there one clinician helping your son or is it a variety of clinicians?

MS. ALMALITI: So with the ABA, we have a team of therapists that work with my son. What ABA does—and, again, I’m not a clinician—but it breaks down the tasks that my son needs to learn. So, for example, if it’s learning how to eat with a spoon, my son would first have to learn how to just pick up the spoon, and then he’d have to learn how to bring the spoon to his mouth, and then he’d have to learn how to accept the food, and then he’d have to learn how to swallow. It just breaks it down into smaller tasks so that he can learn how to do it independently.

SENATOR STEINBERG: And what about the speech portion of it again?

MS. ALMALITI: In the speech portion, my son could not speak. He was nonverbal and he's still, to this day, functionally nonverbal. He had no communication system. And now he has a way to communicate his wants and needs.

SENATOR STEINBERG: Okay. Thank you. Thank you very much.

Let's hear from Dr. Firestone.

MS. ALMALITI: Can I just also just—I want to say one thing. You know, when my family went through the regulatory agency, the DMHC, back when—you know, this was almost two years ago—it used to be, you know, you asked first treatment from the health plan. The health plan denies it based on a number of reasons; and then it goes to Department of Managed Health Care; you appeal their denial; and it goes to an independent medical reviewer, a doctor who's licensed in the state of California, who doesn't work for health plans, and is anonymous, and they decide on the case based on the medical records and the treatment that's requested.

Now, and since March 9, that has changed. The doctor recommends a treatment for the child. You get a denial from your health plan, but now the health plans have basically closed the ranks. There used to be only two ways to deny a treatment. It was experimental or not medically necessary. They have come to an agreement where basically they said, if we deny it based on an educational treatment or an educational therapy, then that—it doesn't say those two words, *experimental* or *not medically necessary* and it circumvents the whole IMR process.

So then what happens after that? Basically the Department of Managed Health Care will ask your doctor, whoever's prescribing the treatment, for a letter with four specific questions on why this treatment is medically necessary. And if you don't answer it, if your doctor does not answer it in a very specific way, that process is not going to go through. It's going to end right there. And doctors don't know how to answer those letters because a lot of the people that do ABA are not licensed healthcare providers. They are not psychologists; they are not, you know, psychiatrists. They are primarily people with a BCBA that

supervise a program and therapists under them run it, and that's what doctors know. That's the standard in all the United States, and there's an independent certification board that oversee these people.

But anyway, so you go and you have to get this letter. If it's not written in the right way, it stops. Let's say it is written in the right way, what happens, the Department of Managed Health Care sends it to this executive committee, and the executive committee has no timelines. I've seen them sit on cases for over six months before they determine whether the treatment is a covered benefit. Then after that, they make a decision; they send a letter to the health plan. They say, oh, we've decided that this is a—we've determined it's a covered benefit; you know, please authorize this treatment and contact your provider. Then the insurance company basically gets back to you whenever they feel like it, whatever is considered a reasonable amount of time, and then they try to find you a person in network, which they don't have any people in the network. They've extended the process from maybe what it used to be, 90 days. I mean, I spent a year and a half fighting with my health plan because I didn't know my rights, and I only spent, like 90 days in the regulatory process. Now families are spending one month fighting with the health plan and a year-and-half or more in the regulatory process.

SENATOR STEINBERG: Which is why I just say, to preview what I would say at the end of the hearing, while clarity by regulation or by legislation is absolutely essential here—and, you know, we need to sit down constructively with the health plans; we need to sit down with you; and we need to work this out, and it needs to result in a bill—my view, as opposed to regulation, a bill, that we can move through the legislature to clarify this on behalf of the families and in a fair way, in a fair way, and that's what's going to come out of this hearing here. That's what's going to come out of this hearing today, okay? (Applause) That's what's going to come out of this.

Dr. Firestone.

DR. BARBARA FIRESTONE: Well, I'll make this brief. I appreciate the opportunity to address you, Senator Steinberg, and Members of the Select Committee.

I want to go back just for a moment to 2005 when the Blue Ribbon Commission began its work under your leadership and vision, and one of the major issues that was brought to our attention through the grassroots efforts of parents and advocates and consumers, parents like Feda and Kristin Jacobson and Karen Fessel, was the enormity of roadblocks and challenges that parents faced in their mission to secure services, medically needed services, from healthcare insurers for their children. And when we looked at this Blue Ribbon Commission, we said that we're going to look at all of the systems of care and we're going to look about how they should be working together. We weren't looking to say, well, this is just the domain of education; well, this is just the domain of healthcare insurance. We were looking for them. We were looking what exists, what are the gaps; how can we cure these gaps and how can we get them to work together synergistically to advance the wellbeing of children with autism.

A child with autism doesn't push a button at 9 o'clock in the morning and say, now I have autism; I'm going to school. And now at 3 o'clock in the afternoon, school is finished so now I don't have autism. It is a lifelong, 24-hour-a-day, medically handicapping condition that needs to be addressed by the co-articulation of several systems of care working together. So no one is asking the system—no one is asking education to abrogate its responsibility by asking the health, private healthcare, insurers to step in. No one is asking regional centers and the Department, DDS, to forgo their responsibilities. We're looking to bring them altogether.

Senator Steinberg, I know you recall—I won't go through the recommendations of the Blue Ribbon Commission and Insurance in the interest of time because we know them all, and we've heard all of the issues still echoed this morning. But one of the results of the Blue Ribbon Commission was that, in the bills that were introduced for the autism

legislative package was SB 1563 which would have required the Department of Managed Health Care and the Department of Insurance to establish the autism workgroup for equitable health insurance coverage to review guidelines and standards on the screening, diagnosis, assessment, and treatment of autism with recommendations to be developed by October 1, 2009, consistent with conformance to AB 88. The legislature passed this bill. The governor vetoed 1563, and I think it's important to mention his veto message as we sit here this morning:

"The provisions of this bill are currently being accomplished administratively through the Department of Managed Health Care. Therefore, this bill is unnecessary and duplicative of existing work. For this reason, I am unable to support this bill."

May I say that it is now almost three years later, and parents and consumers are still struggling with the very same issues that were being addressed by the Blue Ribbon Commission and by that bill. We now, in closing, let me say in my capacity, as chair of the Statewide Council of Autism Taskforces, we had the opportunity to present to the Select Committee on April 13th the recommendations in the insurance area, and I won't go through them. They're all part of your record and they reflect the work of the Blue Ribbon Commission and enhance it and really address many of the issues that were covered this morning.

I, in closing, just want to say Feda is sitting next to me. She is one parent but she is representative of hundreds and hundreds, probably thousands, of parents in the state of California who face roadblocks and obstacles each and every day in securing the rights for their children with autism. So I want to say thank you to you, Senator Steinberg, and Members of the Select Committee for making this meeting possible where we could bring all of the players together in one room to discuss the situation as exists today and hopefully how we are going to move forward on behalf of individuals with autism and their families. Thank you.

SENATOR STEINBERG: That will be the next step. Thank you very much, Dr. Firestone.

MS. LORRI UNUMB: My name is Lorri Unumb. Thank you for the opportunity to testify here today. I'm the parent of a nine-year-old child with autism. I'm also an attorney. I'm formerly with the U.S. Department of Justice in Washington, D.C. I'm also formerly a law professor. I used to teach at George Washington University Law School. But I gave up my legal career to advocate full time on behalf of individuals with autism when I saw the inequity in the insurance arena, so now I am senior policy advisor and counsel with Autism Speaks. I was invited here today to discuss the national landscape. I do work almost exclusively on autism health insurance reform, and I also teach a law school class on the side called *Autism and the Law*.

When my son was diagnosed with autism in 2001, there was one state that offered meaningful health insurance coverage for autism and that was Indiana, and Indiana had taken that step because Congressman Dan Burton's grandson was diagnosed with autism. The same was true in '02, '03, '04, '05. And when I started looking at the issue in 2005—and I was still teaching law school at the time—I considered, is this an insurance problem, an education problem, a Medicaid problem? What is it? And I decided to focus on health insurance because I thought it was the piece of the puzzle that was least trying to help these kids with autism.

I read an article in the *New York Times* from 2004 that said 17 states have health insurance coverage for autism and I thought, that's not consistent with what I'm seeing. I see one state that has meaningful coverage. The *New York Times* says 17 states have coverage for autism. Well, what I then learned was that 17 states had mental health parity laws that included autism within the list of diagnoses that must be covered. In none of those states, however, was ABA being consistently covered. So at that time in 2005, I wrote a piece of legislation for the state of South Carolina that wasn't autism specific health insurance mandate. That legislation passed in 2007; and since that time, 20 other states have passed autism-specific health insurance bills. All of those—

actually, the 21st state was signed into law this morning since our hearing started. In all 21 states, ABA is being consistently covered, and it's clear in the law or through regulations that it must be covered.

Now I also want to add that I have testified in many of those states; and in all of those states, the very issues that you've been addressing this morning about the dichotomy between educational and medical services has come up. The legislature has addressed this issue in all 21 states and has decided that health insurance companies should be covering ABA for autism. And I'll tell you—let me back off of my lawyer hat for just a minute and say as a parent how I look at that very issue. As a parent, my child got diagnosed with autism in a medical doctor's office. It wasn't something that the school principal sent a note home and says your child has autism. You get diagnosed by a medical doctor, and treatment is prescribed by a medical doctor. That really ought to be about the end of the inquiry, in my mind. I have private health insurance. I pay premiums for private health insurance. And thus when my child's medical doctor tells me, here's the treatment protocol that you need to have for your child, I expect my health insurance to pay for it and to contribute to it.

Let me address—I know you have to go...

SENATOR STEINBERG: Please.

MS. UNUMB: Really quickly, the insurance panel brought up the report of the American Academy of Pediatrics and said that it deems ABA educational. Let me just say two quick things about that.

One, that report came out in 2007; and as I have just mentioned, in 2007, there wasn't an option to get ABA covered through your insurance, other than in Indiana. And so that report was just an instructional guide to pediatricians to help them tell families what to do. It would not have been very useful for the ABA to tell pediatricians to tell families, go get ABA through health insurance when it wasn't covered by health insurance at that time. They deemed it as educational. They labeled it educational because that was the only place you could possibly get it at the time. And also, that same AAP report calls speech therapy an educational intervention as well. That doesn't

mean that it's not appropriate for coverage by health insurance. That just means it's something that is available in schools. So it's really a false dichotomy between educational and medical.

SENATOR STEINBERG: That was very helpful, the last point, to hear the other side of the story on the American Academy of Pediatricians.

I want to end with a couple of things from me and then we'll take the public testimony.

Dr. Firestone, I don't think we've done this yet in this hearing. Define ABA therapy, please.

DR. FIRESTONE: It's a behavioral intervention strategy...

SENATOR STEINBERG: Yes?

DR. FIRESTONE: ...that is used to help children develop or extinguish or modify certain behaviors. It's incremental. It is very...

SENATOR STEINBERG: It includes who?

DR. FIRESTONE: It is very consuming. It generally includes the child and the facilitator. I hesitate to use the word *therapist* in this context because it's generally someone who works under the supervision of someone who is a licensed professional and it could be for as much as—could take an hour a day; it can be prescribed for an hour a day, two hours a day, four hours a day, six hours a day, just varying degrees, and it breaks down behaviors into their most incremental, smallest steps.

SENATOR STEINBERG: What I want to understand here—is it one person who works with the child or is this case manager, which is what I'm thinking as you're describing this person, the facilitator of a variety of services under the umbrella?

DR. FIRESTONE: It's one to one. It's intensive. It is between that facilitator or that therapist and that child. It is very intensive; it is very demanding; and it is typically supervised by a licensed professional. That tends to be the standard of care in the community right now.

SENATOR STEINBERG: Okay. Thank you.

I know Senator Pavley has to catch a plane. And again, I want to just thank everybody, the panel and all the panels, for a most illuminating couple of hours here that reinforces my commitment to try to solve this problem and challenge.

MS. ALMALITI: That's an ABA methodology, reinforcing behavior.
(Laughter)

DR. FIRESTONE: Positive reinforcement, yes.

MS. ALMALITI: Positive reinforcement.

SENATOR STEINBERG: It worked on me. (Laughter) There you go.

A couple of observations, and we can talk about again the interpretation of the law, and that's real and important and there's a lawsuit apparently. And the legislature, of course, at the end has the right to weigh in and interpreting it in its own way. But fundamentally here, I think the disagreement with the providers really has to focus to a large degree on the actual efficacy, cost-effectiveness, human effectiveness, medical effectiveness, of ABA therapy itself because that's really what's at issue here. And I will say that in medicine and in society, it is in our interest and it is in, I think, even the provider's interest, to consider and settle on best practices.

For example, when we talk about cancer, the best practice now for treatment is chemotherapy and radiation. That's what we do. Even when it comes to mental health and, in many cases, autism, the plans do cover psychotropic medications. Those psychotropic medications are intended to change the brain structure, if you will, or the brain chemistry, but they're also intended at the same time to help people living with mental illness or with autism address some of the behaviors, if you will, associated with having those conditions and yet you cover that. So I think fundamentally, as we consider a legislative path here—and, you know, my way is always to want to do it collaboratively—that we need to grapple with the real question here which is the efficacy, effectiveness, appropriateness of ABA therapy as a best practice. It either is or it isn't. And the great frustration here, I think, is too much nuancing, right? Well, if proven in this case, we'll authorize it. I think you

either should or shouldn't. I think you should. But let's grapple with what it is, ABA, and think about it, I think, in the same way we think about best practices in other parts of the healthcare spectrum.

I will convene meetings in my office, post-haste here, to begin grappling with this. I know I have a couple of bills moving through the process, sort of the general topic, and we have a couple of months left in this legislative session and I'd like to fill one of those bills in with the right kind of deal, right kind of solution—excuse m—and, again, with all of the important stakeholders at the table.

Thank you, thank you. I'm going to excuse myself.

Dr. Vismara or Fran, do you want to take the public testimony?

SENATOR PAVLEY: Go ahead and let Dr. Vismara. I'm going to stay as long as I can and I will listen to the testimony...

SENATOR STEINBERG: Okay. Great. Thank you, and thank for everyone who's waited patiently.

DR. LOUIS A. VISMARA: ...(Gap in hearing from 02:16:41 through 02:17:17)... Again, thank you very much. This hearing is being televised—it's taped—and we will be sure that copies of the videos are distributed to all of the members of the Senate Select Committee. So maybe we can just ask for the public testimony and public comments.

Senator Pavley, you think we should limit it to a few minutes or...

SENATOR PAVLEY: Maybe you can see how many people are going to speak and are here. It's your time. I will be leaving in a half hour.

DR. VISMARA: I think we have five chairs up here so we'll first invite Connie Lapin, Chuck Genseal, Jim Lantry, Jane Howard, and Dennis Hart to come forward.

SENATOR PAVLEY: Maybe two or three minutes each and submitting things in writing...

DR. VISMARA: Excellent, yes, I think that would be great.

MS. CONNIE LAPIN: Hi. My name's Connie Lapin. I'm in awe of this hearing. The reason I came up, I am a speech pathologist but, more important,

I'm the mother of a son with severe autism but I want you to hear his age. You might want to ask why I'm here. He's 42 years old. So I have had a very rich history of understanding autism, trying to figure out the treatment, and fighting for services. And may I say in front of all of you in this building, I'm so glad you addressed the different issues, but I remember in 1973 when we had Senator Alan Cranston, if any of you remember him. He put autism in the Developmental Disability Act because that was the days when it was, you know, the mothers that did it. Then we had Senator Burton in this building that passed the first bill to educate autistic children that said, hey, our kids, our people, can learn and have faith. And then I'm going to pretend Senator Steinberg is here, and I know he'll hear this, and I'm talking to all of you, I want to say to you, now I want you to be our hero like you have with the Blue Ribbon Commission and like you are today.

We need to pass something here. I'm a speech pathologist and I can see, when we talk about what is it, medically or educationally, it could be both, and I think what's happening and my frustration is, this isn't exact science. Somebody decided—and I loved what the person said from Autism Speaks—it was a guideline and now it's taken a life on its own. So what I want to say to all of you very briefly, I don't want to have you and other young parents be here in 40 years and say, well, we had this hearing. I mean, you may laugh, but I in 1973 thought we had this situation under control. So please pass a piece of legislation that makes sense to all of us. Thank you.

DR. VISMARA: Thank you.

Chuck.

MR. CHUCK GENSEAL: My name is Chuck Genseal. I am a grandparent to a sweet nine year old by the name of Michelle diagnosed with autism, Rett specifically, a degenerative, debilitative condition. Michelle has depended on the Frank J. Lanterman Act, 1968, to get services from the California Department of Disabilities. Hence, it has been Michelle's healthcare provider for OTPT behavioral and speech services. Californians' downturn in revenues has had a negative impact on delivery of autism services for the

epidemic of ASD. California, because of its budget pressures, has been focused or forced to develop cost-containment measures. Michelle's autism cannot be legislated or underfunded away.

The missing component in this puzzle of autism is the responsibility of the healthcare insurance industry. Autism is indeed a healthcare issue. Michelle's healthcare provider, Kaiser, has systematically denied the very services needed by my Michelle. Michelle's quality of life is negatively impacted by Kaiser's refusal to deliver OTPT and SLP services, and that is in contrast to what we heard these service providers stand up and say they provide. They do not provide that, and they do that under the guise of medically unnecessary. The denial as recent as April stated that "services recommended by an outside provider". That is a quote Kaiser put on the denial which is currently sitting at the Department of Managed Health Care Services. I hope I just don't become another statistic.

Kaiser's premiums are paid in anticipation that Michelle's healthcare needs will be met. Instead, Michelle's services are denied. I would like to see the state of California exit being a healthcare provider, which it cannot afford and be replaced by the insurance industry which can well afford it, as evidenced by the profitable and bonuses and the history of the Kaiser.

I personally will settle for nothing than an insurance mandate that tells these people they will take care of these services. They will spend the next ten, 20 years telling us to define this, clarify that. I think we can accomplish the same thing by telling them they will cover autism and all autism services. Thank you very much.

DR. VISMARA: Jim?

MR. JAMES LANTRY: Hi. I'm Jim Lantry. I represent a group of parents of children with autism who use Floortime/DIR services to treat that.

Yesterday we had a rally at the Capitol and we met in the offices of many of the people, many of the members of this committee, including yours, Senator Pavley, and our message was simple: Parents need a choice of treatments. We listened to Dr. Amaral talk this morning, if I understand it correctly. And not

being a doctor, I don't. But just in case, he said the 20 percent of the incidents of autism are caused by genetic differences. But of those 20 percent, less than 1 percent are by any one genetic cause. It shows that there is such a huge difference in the causes of autism or the way we get to autism. There's also a huge difference in the way it manifests itself in our children, and there's also a broad spectrum of treatments that are necessary because not one size of treatment fits all.

Senator Alquist talked about needing definitions, as did Senator Steinberg. And we agree. Unfortunately, I think that when we use the word *ABA* sometimes, we really mean, as—I'm sorry—the person from the Department of Insurance—I can't remember her name—I'm sorry—mentioned that we were really talking about intensive behavioral services. I think intensive behavioral services is a term we should be using. *ABA* is an intensive behavioral service, as is *RDI*, as is *Floortime*, as are a number of others.

Some children respond very well to *ABA*; some children don't. Some children respond very well to *Floortime*; some children don't. But the point we need to do is make sure that the evidence-based practice that we're using is one that works with that particular child. And to get into definitions, which I think are very, very important, we need to stop using the term *ABA* as all inclusive and start using the term *intensive behavioral services*, including *ABA* and the others. This is a critical thing because, as long as we use *ABA* like we use the word Kleenex when we really mean tissue, we're going to find that we are excluding a lot of children from very necessary therapies, and I will tell you that a lot of these children have tried *ABA*. It didn't work. Some of them have had a combination of *ABA* and *Floortime* or *RDI* or some of the other services, and that has worked for them. We need to make it work for them. We need to do it cost effectively but we definitely need to do it in something that's tailored to the child. It is a medical necessity.

The other issue I wanted to bring up that we mentioned yesterday is another class of Californians that are dealing with problems with autism and that's military families. Military families have a huge problem, not just in

California. But for some reason, the incidents of autism in military families is greater than it is in the normal population. Nobody knows why, but then again nobody understands the causes of autism either. But the one thing you can say about a child with autism is that they crave constancy. They don't like change. And the one thing that's constant about a military family is change. You've got constant deployments; you've got constant reassignments. Children need to have some additional help. And on top of that, when you're changing from one state to another, you find that there are services offered in one state that may not be offered in another. Or if they are offered in that state, you end up at the bottom of a long waiting list to get those services.

The children of families that are sacrificing for this country deserve better, and there is a bill that will be introduced in Congress in the next couple of weeks that is going to ask TRICARE, the military medical health insurance, if you will, to fully fund intensive behavioral services. Again, I use intensive behavioral services instead of just the ABA because it will encompass all the things. A Joint Resolution is in Legislative Counsel asking the legislature to endorse this effort and asking, memorializing Congress to pass that on behalf of our military families. This will have a great impact on California and a great impact on our families, and I would encourage every member of this committee to coauthor this resolution once it's come out of Legislative Counsel, and I will be in your office to ask you to do that but thank you very much.

DR. VISMARA: Thank you.

Jane.

MS. JANE HOWARD: My name is Jane Howard and I'm here representing the California Association for Behavior Analysis, CalABA. That's the professional state association for behavior analysts. And applied behavior analysis is the only behavior intervention that has been consistently documented to produce significant and meaningful improvements in children and adults diagnosed with autism spectrum disorders in the scientific literature, not other methods. It is ABA and that's why we've been using that term today.

The majority of our membership is composed of board-certified behavior analysts who are the professionals who have met the requisite level of formal and experiential training and other objective standards as specified by the behavior analyst certification board. That is the professional credentialing organization for the field of behavior analysis. And I guess one thing that I would say, as perhaps that I'd correct or differ with Dr. Firestone is that most intensive ABA services are coming under the auspices of a board-certified behavior analyst, not typically a licensed psychologist, although I, myself, am a licensed psychologist and a board-certified behavior analyst. The actual standard of care and the requirements for folks who should be supervising these treatment programs are spelled out in great detail in the consumer autism guidelines put out by the Association for Behavior Analysis International, their autism special-interest group, if anyone in the committee is interested in seeing them.

I think some of the most important tasks remain ahead. It's clear that in many states autism coverage is mandated, that ABA is viewed as a medically necessary treatment, and that it produces substantial benefits for individuals with autism. What needs to be worked out are the terms of coverage, services with the health plans. Maybe that's going to happen with regulation with, by law. What I would like to tell you is that CalABA and the BACB—that's the Behavior Analysts Certification Board—plan to work those details out. We want to work with Senator Steinberg's staff and other government entities to make sure that all the consumers in California who would benefit from this kind of intervention have access to the science and practice of applied behavior analysis at the highest level.

Thank you for the opportunity and for spotlighting this very important public health problem.

DR. VISMARA: Thanks.

Mr. Dennis Hart.

DR. DENNIS HART: It's actually Dr. Dennis Hart. I am a pediatric rehab medical director for Sutter Health. I am also one of those anonymous

reviewers that review for one of the contracted people through the Department of Managed Health Care. I review a lot of the speech therapy and occupational therapy evaluations that come to IMR.

About 70 percent of the ones that I review come for the diagnosis of autism, and so one of the things that I wanted to relate today is to your question, Senator Pavley. I oftentimes get information about what's being denied for the entire services, not just speech therapy or occupational therapy. And I can tell you that there are a large number of cases that deny ABA therapy. They don't do it based on medical necessity. They go around and are circumvented as the one mother purported. I can also tell you, I've been doing this for about ten years now, and the timeframe for review has gotten longer and longer and longer, and I'm oftentimes seeing cases that have been denied, where it's taken 180 to 360 days. I've had literally a year or more for those denials and the whole process, and so I think that really needs to be corrected.

I think the other issue that I am trying to look at from a broader standpoint is, What is the care coordination and who is managing that care coordination? There are, when I'm reviewing my cases, a lot of times I'm trying to determine between, Is this an educational problem or is this a medical problem? And just as Dr. Rogers had decided that it comes down to function, that's exactly the approach that I have taken, and they give me great leeway on how I determine things. But I basically decide whether this is a functional issue or an educational issue. And in most cases, the insurance companies are denying clients based on what I consider functional needs.

Part of the problem that I see, though, is that there is no one person who oversees standard or care coordination for kids with autism. I'll contrast it to what I do in my regular practice. In my regular practice, probably about 70 percent of the kids that I take care of have cerebral palsy; and in that practice, my responsibility is to overlook it for their entire healthcare needs. I deal with their GI issues; I deal with their pulmonary issues a lot of times. I have other specialists that I work with, but I often see myself as that primary care provider who provides for not only their healthcare but what their quality

of life is. Quality of life really is affected by their medical condition. Quality of life affects education. It affects their community, ability to get out into the community. We need to establish someone who can become that child's coordinator so they can say, this part of ABA is an educational issue; this part of ABA is a medical issue and really coordinate that.

One of the problems that I've seen with autism is the people who "treat" autism in the medical community typically are providers that diagnose. And once they diagnose, it goes out to the community for treatment, and they aren't given the opportunity to follow up and follow that patient on a serial basis. A child with cerebral palsy, I will see them every six months and I'll review both their medical needs, their educational needs. I'll often counsel the families on how to deal with the IEP. I will get in contact with them on how to deal with the IEP process. I don't see that in the medical community for autism, and I think that we need to establish that medical director that really helps determine what the needs of the child are to improve their quality of life and their healthcare. Thank you.

DR. VISMARA: Thank you very much, Dr. Hart.

A quick question, if I may. One of the gentlemen—I believe it was Mr. Andrew George—indicated that the number of IMRs since 2001 were meant for behavior intervention therapy were only 33. I believe those are the statistics that he quoted. That seemed to me surprisingly low numbers.

DR. HART: Well, I think he's talking specifically for ABA.

DR. VISMARA: Right, but even for ABA.

DR. HART: Well, in my experience, what is happening is it never makes it to the IMR process.

DR. VISMARA: I see.

DR. HART: That was what I was referring to, to you. It never makes it to the IMR process. Speech and occupational therapy will often make it to the IMR process. ABA rarely makes it to the ABA process.

SENATOR PAVLEY ??: _____.

DR. HART: Exactly, exactly.

DR. VISMARA: In terms of the prolonged appeals process, the bill that Senator Steinberg introduced this year, SB 1283, again deals with this issue by setting specific guidelines and timelines by which DHMC would have to resolve that and removes the discretion to hold it indefinitely, so we are very appreciative of this issue and have a bill to address it, so thank you for your testimony.

DR. HART: Thank you.

DR. VISMARA: Thank you for everybody.

If we could have the next group of people for public comment, including Karen Fessel, Laura Schumaker, Ann Mohan, Mr. Craig King, and Kristin Jacobson. Welcome and thank you.

Karen?

MS. KAREN FESSEL: Hi. I'm Karen Fessel. I'm a parent of a 15-year-old son with Asperger's, and I've also become a healthcare advocate. I have a public health background. I have a doctorate in public health. And when my child was affected, I found out when my child was affected, I turned first to my healthcare system because I am a health professional and that's what I knew best, and I was shocked to find out how hard it was to get services.

After I went back to work—and now I help other people advocate, other parents advocate, and get services for their kids. I help families every day, and what we currently have in terms of the law, is just not enough. And every person has to go through on a case-by-case basis, in terms of getting the services that their child needs because the health plans, first off, deny.

We talk about budget problems at the state level and how severe the budget crisis is, but what's going on right now at the Department of Managed Health Care where cases sit and sit and sit and the DMHC lawyers think about what's going on, that's costing the public more money than it would cost to either mandate the services or to send them through to IMR because, if they go through to IMR, then they become—the costs of IMR are borne by the health plans and not the state itself. So a mandate will ultimately save the government money for a variety of reasons that will help pick up some of the

costs that are currently being borne by the regulatory system and will also treat the symptoms of autism and the people that have it and it will reduce the amount of disability, both in the long term and the short term, and it should cover some of the expenses that are currently being borne by the regional center and the state and the school educational system because the educational system is dealing with many issues that this committee today has determined are medical.

Then I had a couple of other comments that address some of the issues that have been, that have been batted around. I've seen several denials where they've denied saying that they don't treat behavioral problems, that where the insurance companies will say they don't treat behavioral problems, and I guess what is the point of mental health treatment but to treat behavioral problems. That is ultimately what we want, to be able to impact on behaviors, so I thought that was like a really weird denial that we're seeing a lot of lately.

I wanted to speak to what the doctor just spoke of before where he said that we need medical directors that sort of are the case managers for people with autism, and I have someone like that and he's awesome and he is a developmental pediatrician, and I consider him the captain of my son's team, and he's—the irony of it all is that I'm really good at getting services for my son, but he's the one thing that I pay out of pocket and they don't offer in network. And they do offer some developmental specialists but they're not—they don't offer the checking in on a regular basis, and it's been the one thing that at times, I've been able to get it and at times I haven't. But the irony is that it's something that is not available just generally. Thanks.

DR. VISMARA: Thanks, Karen.

Ann?

MS. ANN MOHAN (sp?): My name is Ann Mohan and I own a rehab center for mental and physical impairment, and I'm also part of the current Autism Regional Taskforce.

It is apparent that we are going towards passing a legislator ???. Like Lorri had mentioned, in our research, we also found Indiana to be one of the states that qualifies as legitimate coverage for ASD.

I just want to make one recommendation, is that we should use states, such as Indiana, as an example of what are those laws, what services are covered under those laws, what is working, and what may need some further clarification. How do they clarify such things as medical necessity criteria versus education? What is in the law that gives power, and what are some of the challenges that is currently being faced in the current law, such as states as Indiana? How are denials addressed—medical versus education, number of denials since Indiana has passed such laws, and what is the appeal process that they are using? We should be using—we should not reinvent the wheel but build on a system that is already working.

DR. VISMARA: Thank you.

Kristin.

MS. KRISTIN JACOBSON: Hi. My name is Kristin Jacobson and I am right now a consumer advocate as well as a parent of a child with autism. In my career, I spent the last 20 years doing healthcare reimbursement and for device companies, drug companies. And when my son was diagnosed with autism and I started asking around, well, what kind of treatment could I get for my son from the insurance, I was astounded. I've never seen a condition that has been so successfully and categorically denied by all insurance. I found it frankly particularly appalling to hear the sort of counterbalance between the doctors who started saying, this is the gold standard, medically necessary treatment of autism, his ABA, and the most effective to ameliorate the symptoms of autism. And then when Senator Steinberg asked the question of one of the health plans—I believe it was Kaiser—of how many cases have you actually approved of ABA therapy, and the answer was one.

That seems to be a fairly significant disconnect between the standard of care and what's actually covered. It just speaks for itself. Also, I just wanted to—another sort of point of confusion, Senator Steinberg had of the

Department of Managed Health Care, when he was saying, well, it seems like if a doctor recommends a treatment and says it's medically necessary, then you're going to send it to IMR. And the health plans were—I mean, the DMHC was saying, well, as long as it says that it has to be provided by a licensed provider, and I think that is the distinction that was causing the confusion of why aren't these cases going to IMR? Why are there only 33?

Up until 2008, nobody knew you could send something to IMR. From 2008 to March of 2009, 20 cases on ABA went to IMR. That's because 20 cases were submitted and they all went to IMR, and I think 100 percent of the ABA cases won. I mean, that's not controversial. If the doctors make the decisions, 100 percent of the cases win. Then, since March 9, there's probably been four or five cases that have gone to IMR, maybe six or seven. But I think probably the numbers that have been submitted and requested for IMR maybe would be 70, 80, 90, 100. So the cases are not going to IMR, and the distinction is that the doctor—normally you would just think: I'm a doctor; I say it's medically necessary, and I say why. But they were requiring you to also say it has to be done by a licensed provider. No doctor would know that they have to write that in order to get it sent to IMR, and so that has become a systematic way of not sending things to IMRs. The lawyers say they don't want to be deciding medical necessity but they are by not allowing the doctors to decide medical necessity. Again, 100 percent of the cases are decided that this is medically necessary. So that's where the numbers and that's where the confusion is of, well, if it seems like your policy is clear, it would be unusual in a treatment plan to say, they need heart surgery and please make sure that the doctor providing the heart surgery is licensed. They need, you know—and the amputation, please make sure the doctor has a license. That's not something that you would write, and also the health plans know, if that statement is not written, then if they control them, the HMOs that control their doctors, the doctors aren't allowed to write the statement that it needs to be provided by a licensed provider and so it can't get to medical review. It can't get into the hands of the doctors for the doctors to make the decisions.

Health plans pay for lots of treatment by non-licensed individuals. EEG techs don't have to be licensed, interns. Medical arts has a long and varied history of using non-licensed providers to implement the healthcare under the direction and guidance of licensed and certified providers, and the law says *and certified providers*. There is no requirement in California law that ABA be done by a licensed provider. The only requirement is that you must follow the licensing laws of the state. There are no specific licensing laws of the state.

If you get back to it, what Senator Steinberg says is important, medical necessity, that's what's important. The law says that health plans must provide medically necessary treatment for autism. You can't decide if it's covered first and then only if it is decide if it's medically necessary. If it's medically necessary, it has to be covered, so that has to be the first question and everybody shouldn't have to appeal because, once you have 100 percent wins, it's not controversial. It is medically necessary for autism. The only case should be going to medical review at this point is, it's not necessary for this child because they no longer benefit or it's shown not to be effective. But as a category, ABA is medically necessary for autism, and each case should not have to be fought.

I think the confusion that's out there is one that's unfortunately being generated and promulgated by the health plans. The medical community is very clear on what is evidence based and what's medically necessary for autism. The providers are clear, even the whole educational medical distinction. Part of idea that governs education law says that many educational treatment or many medical treatments may be necessary to allow a child to access their education. In fact, a school district can go after medical insurance to have the treatment covered by medical insurance, as long as the parent consents and as long as it doesn't adversely affect their medical care. So just because something may be necessary for education doesn't mean it's not medical, and I think it's worth getting some consumer advocates to give their interpretation of the law because it would differ significantly from both

what the health plans and the Department of Managed Health Care said which is why there are lawsuits underway.

I guess in the end, I would just say, I think it's pretty clear what needs to be done. It's clear that these treatments need to be covered, and I think probably at this point the legislature is the only body that may be capable of putting together some legislation that would allow that to happen.

SENATOR PAVLEY: Maybe it's an ignorant question, but obviously things change in the way you complete the forms or fill out your cases before it goes to IMRs since March 9th. Within the medical community, especially the pediatricians, hasn't there been an attempt for communication on the fact that things have changed and you need to fill out the forms for your presentation?

MS. JACOBSON: I can't speak to how many pediatricians and physicians there are in the state of California, but I can only imagine that there are tens of thousands or...

SENATOR PAVLEY: That wouldn't know that...

MS. JACOBSON: That wouldn't possibly know. And I think the other thing is that the statement, that it has to be done by a licensed provider, there's no basis in law that that statement even should be necessary so it's an erroneous, unnecessary requirement that's being placed on the consumer. And you can't go to Kaiser and get that statement written. It's just not possible. So if you have Kaiser health insurance and you need that statement written, you'd have to go pay for a private clinician to write that and you'd have to know. And unfortunately, I wish we could clone Karen and Fedra and myself and Lisa a thousand times over because I think, you know, there need to be a thousand of us to figure out...

SENATOR PAVLEY: I've heard this several times today.

MS. JACOBSON: ...how to write those letters.

SENATOR PAVLEY: Yes, how to write the letters.

DR. VISMARA: Let me welcome and thank Senator Roy Ashburn for being here. We're just wrapping up the public testimony. Would you like to make some comments?

SENATOR ROY ASHBURN: No. I've been following the hearing on television as I've been to appointments, and I appreciate everybody's participation.

DR. VISMARA: Thank you.

Mr. King.

MR. CRAIG KING: Don't worry. My remarks will be brief.

DR. VISMARA: Is Lisa Valerio—maybe she can join us as we're finishing and also Dave Gaines.

MR. KING: Yes. My name is Craig King. I'm the president and CEO of Easter Seals, Northern California. We provide a variety of services to people with disabilities, including early intervention, for people with a wide range of disabilities, including autism, and our early intervention model is grounded in a tradition called DIR/Floortime. So I want to echo some remarks made by another one of our witnesses today, that it would be costly and I think premature for the state to conclude that ABA is the only suitable treatment option for people with autism. In fact, there is a longstanding body of evidence, clinical evidence, that DIR/Floortime is quite effective for people with disabilities, including people with autism.

It's important to bring to your knowledge that there is a lawsuit, actually, a preliminary injunction, that was successfully brought in Los Angeles Superior Court by a group of seven parents on behalf of their children ordering the regional center to continue funding DIR treatment services, and that ruling was arrived at after consideration of some 2,000 pages of evidence submitted by both defendants and plaintiffs. The court did not find the National Standards Report that was submitted into evidence by the defendants to be persuasive or binding on the court. The court was very concerned that the regional center's decision to terminate funding for DIR would essentially leave parents with one choice of treatment, applied behavioral analysis or ABA.

We heard today testimony that autism has a variety of causes as well as manifestations. The idea that there's only one suitable treatment approach is inappropriate. The judge found that the testimony about DIR's effectiveness

was very powerful. He determined that DIR was not experimental, finding that many physicians and other skilled clinicians have been successfully treating autism using DIR for years.

A very important consideration for this state is cost, and DIR approaches are much less costly than ABA. ABA is reliant on many, many hours of one-on-one individual therapy. The DIR approach is a parent-training approach. It was designed that way from its inception, and so it often costs a quarter or a fifth as much as ABA.

So in closing, we urge the legislature to provide families with options and choice of treatment for their child that includes ABA, that includes DIR approaches, whether that treatment is funded by the state through regional centers, or through private insurance. Thank you.

DR. VISMARA: Thank you. Let me just point out that the title of this informational hearing was *Health Insurance Coverage of Behavioral Intervention Therapy*, and indeed Dr. Sally Rogers, who testified and is a world expert on the Early Start Denver Model, which is a really very eclectic approach that includes a multiplicity of approaches and therapies, so thank you.

Lisa?

MS. LISA VALERIO: Thanks. I'm Lisa Valerio. I'm also a mother of a child who's now turning seven with autism. Like Fedra, I actually fought the insurance companies three years ago and won and where he received three years of really intense early intervention and has made really amazing progress, and I want to be able to do this and help other families advocate to do this.

The one thing that we have found recently—and I know that all the things that had been brought up today—I wanted to just to reiterate. What Kristin and Fedra had said is that things are just being hung up when it gets to the DMHC. I have cases that are just sitting there that's been there for three or six months.

The one thing that we have found, though, is that when we do find that we can write these letters in a particular way or get the pediatricians to

actually, you know, show the medical necessity and indicate that they need to be done by licensed providers, what we're finding is the last five cases that we've actually put in for preauthorization through various different insurance companies is that they're actually coming back and they're approving the medical necessity, but they're only approving the piece that's being done and supervised by the licensed provider and that is where the child cannot get the services that they really need. So I think, again, they're taking every loophole. Every time we tried it, we say that, yes, it is medically necessary, okay, well, now we're only going to provide it by the licensed provider.

So I think I wanted to clarify that because I have five cases right now, and I'm sure there's many, many more families that are out there trying to do this and they give up. And so I wanted to put some clarity around that, that now we are finding that they're getting approved, but now we're getting hung up only, you know, the five hours that's being done by the licensed provider.

DR. VISMARA: Thank you.

Mr. Gaines?

MR. DAVE GAINES: Do I just talk or do I need to push a button here? You guys are very fancy.

My name is Dave Gaines, and I'm a behavior analyst and a special education advocate. I've been doing behavior analysis for about five years now with children and teenagers with autism and also been doing the special education advocacy for a few years now. I'm also the vice-president on the board of directors of the Developmental Neurodiversity Association, a new California, nonprofit corporation, and that's primarily why I'm here to speak representing that organization.

As a public benefit corporation, I'm not here to influence the legislation but rather to present some factual information which has been left out and is commonly left out of situations like these and it's relevant to the topic matter, and I'm not going to speak for either side of the argument, whether autism, ABA therapy should be covered by health insurance or not.

There was representation of consumers here, but there really wasn't a representation of consumers here. There were parents of consumers who are very important people in this process, but unfortunately we do not have any actual consumers of services which are people with autism, whether they be children or adults, and let's not forget that there are a lot of adults with autism. This is not just a child's situation.

The reason I came is because this debate has a lot to do with, Is autism a medical disorder? What I'm here to say is that there is a question as to whether autism is a medical disorder, for sure, and there's actually a very substantial question as to whether autism is a disorder of any type, whether it is a label of developmental, behavioral, or medical disorder.

There is a very quiet voice in the autism community and in the issue, and that is, the voice of autistic people who can't express themselves. And there are a large number of autistic people—kids—you know, maybe about 13—teenagers, and adults who are voicing their opinions on autism and what it is, what kind of—you know, is it a disorder; is it not? And the internet is a great place to find this stuff because people with autism are very good at using computer devices. That's where you can find them communicating about these issues.

So what you have is a group of, a large group of people with autism. In fact, if you could communicate with people with autism that you can communicate with, most of them are going to subscribe to the fact that they do not have a disorder of any type but, rather—and the term for this is called neurodiversity and it's the same as racial diversity, gender diversity, religious diversity. The argument is that autism is not a disorder of any type but rather a natural variation of the human condition. It is a different type of neurology. It's simply a different type of mind, just as we have different type of people—black, white, Asian, American Indian, and so on—autistic people are saying, we do not want to be cured; we do not have a disorder; we want to be recognized as a natural, diverse, variation of the human condition.

Now this is a rather maybe shocking or controversial idea, but it is an idea which is gaining traction and an idea which is very significant.

DR. VISMARA: Mr. Gaines.

MR. GAINES: Yes, sir.

DR. VISMARA: I'd just like to appreciate your comments and just acknowledge the fact that within our 12 taskforces, we just have, we specifically have, engaged a significant number of individuals who are on the spectrum and they're fully embraced, and I think your comments with regards to neurodiversity are very compelling, very poignant, and we really appreciate and we could not agree with you more.

Having said that, this hearing is specifically focused on issues of health insurance so maybe, you know, since you have obviously expertise and perspective, could you maybe close your comments with focusing on the issue of the hearing?

MR. GAINES: I can't give an opinion towards either way because I'm representing a public benefit nonprofit.

DR. VISMARA: Okay.

MR. GAINES: So I can present factual information but you can—go ahead.

DR. VISMARA: You've given us some—was this the written material that you submitted?

MR. GAINES: This is quite a bit of written material, including scientific evidence to support it.

DR. VISMARA: Well, we could not agree with you more about the issue of neurodiversity, and we would encourage you to continue in the dialog, participate, get involved with the taskforces, and really appreciate your being here.

MR. GAINES: Okay.

DR. VISMARA: Thank you.

MS. JACOBSON: _____?

DR. VISMARA: Yes.

MS. JACOBSON: I just wanted to mention that there's some other sort of enforcement things that could be considered for future in terms of, we heard that the health plans don't comply with some of the directives from the DMHC and the timing, and I think we could actually do a significant amount to potentially increase the fines for noncompliance and also to not really reward the delay because I don't think that really came up that, but there is a huge financial incentive for the health plans to delay this process as long as possible because in the end, even if they lose, all everyone gets is the treatment for it. So if you delay it for a year, you just saved a year of treatment and you certainly cost, you know, a lot of money.

DR. VISMARA: SB 1283 has such a provision.

MS. JACOBSON: So anyway, there are some amendments actually to SB 1283—I believe you have it. We'll just sort of include them in this testimony from the Alliance of California Autism organizations that looks at, maybe even doing some more things, either in that legislature in the future a piece of legislation where you could put some more penalties and more fines in place.

And on Lisa's point about when they only approve the five hours done by the licensed provider, basically that's an issue of not having an adequate network. If you had a network of licensed providers, it would be perfectly fine to say it has to be done by a licensed provider, but the treatment's medically necessary. And if you don't have the licensed providers to do it, then you need to go with what the standard medical delivery care model is which is supervision by either a licensed provider or by a BCBA certified provider, and I'll just add this to the testimony.

DR. VISMARA: Thank you very much, Senator Pavley, Senator Ashburn, fellow staff.

Any closing comments?

SENATOR PAVLEY: No, but I'm just very impressed with the quality of the testimony.

DR. VISMARA: On behalf of the committee, again, our sincere thanks, appreciation and continue looking forward to working with everyone here. Thank you so much. This meeting's adjourned.

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